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ABSTRACT

This annual report of the National Council on Disability surveys major legal and policy developments during the year 2002 and offers recommendations for legal/policy measures and for research. The first chapter identifies legal and policy issues that cross traditional areas, focusing on six themes: (1) the mainstreaming of disability issues; (2) the rise of the technical assistance model; (3) evidence-based decision making; (4) cost-effectiveness; (5) intergovernmental coordination; and (6) budgetary constraint. The following chapters summarize findings and offer recommendations for the following areas: disability statistics and research; civil rights; education; health care; long-term services and supports; youth; employment; welfare reform; housing; transportation; assistive technology and telecommunications; international issues; and homeland security. Concluding chapters list the recommendations presented in each chapter and summarize major activities of the National Council on Disability. (Contains 120 references.) (DB)

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NATIONAL DISABILITY POLICY: A PROGRESS REPORT

December 2001–December 2002

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National Council on Disability

July 26, 2003

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1331 F Street, NW, Suite 850
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National Disability Policy: A Progress Report
December 2001–December 2002

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Letter of Transmittal

July 26, 2003

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), it is my duty and honor to submit NCD's National Disability Policy: A Progress Report, as required by Section 401 (b)(1) of the Rehabilitation Act of 1973, as amended.

This report covers the period from December 2001 through December 2002. It reviews federal policy activities by issue areas, noting progress where it has occurred and making further recommendations where necessary to the executive and legislative branches of the Federal Government.

As noted in the report, NCD has observed many examples of progress in disability policy. Among these are enactment of the Help America Vote Act for increasing access to elections for Americans with disabilities; establishment of the Presidential Commission on Mental Health to examine and recommend changes in our nation's mental health system; and the Supreme Court's ban on execution of persons with mental retardation.

Despite reforms in disability policy which are intended to improve the lives of people with disabilities, many challenges remain for our citizens who are living with disabilities and who wish to be more independent, more productive and more engaged in their families and communities. Far too many Americans with disabilities are undereducated and unemployed. Many of them are desperately trying to improve the quality of their lives, but they are frustrated by a lack of affordable accessible housing, transportation, personal assistance services, medical rehabilitation and job opportunities. NCD will continue to develop policy recommendations to address these issues.

(continued)

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The Administration's New Freedom Initiative provides a road map to increase investment in and access to assistive technologies and a high-quality education, and to help integrate Americans with disabilities into the workforce and into community life. NCD will continue to work with the Administration and Congress to ensure that every individual with a disability has access to the American dream.

In the past year, NCD has undertaken and completed a number of projects that support the New Freedom Initiative and that respond to NCD's statutory mission. In particular, NCD has completed a series of policy evaluations and evidence-based studies that are intended to measure progress toward implementation of the Americans with Disabilities Act.

NCD encourages all government agencies and Congress to use our work as a reference point and source of data for recommendations, and as a basis for further examination of issues that impact the lives of people with disabilities. NCD stands ready to work with the Administration, Congress and the public to ensure that public policy is shaped in a manner that will provide the greatest possible opportunities for people with disabilities as they strive to be fully productive, contributing citizens.

Sincerely,

Lex Frieden

Lex Frieden
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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EXECUTIVE SUMMARY

The National Council on Disability (NCD) is charged with preparing an annual status report to the President and Congress. In this annual report covering the year 2002, we survey major legal and policy developments over the past year. The report identifies both the progress and deterioration in the conditions faced by Americans with disabilities and in their opportunities for full participation in society.

Based on what has happened, the report analyzes major issues likely to be confronted in the coming year, and makes recommendations for legal and policy measures and for research that we believe would contribute to the achievement of America's widely shared goals, including those of the President's New Freedom Initiative (NFI).

Whether in connection with education, employment, health care or independent living, we find legal and policy discussion to be informed by six recurrent themes: the mainstreaming of disability issues (convergence of disability policy and other issues in ways that no longer allow disability policy to be considered in isolation); the rise of the technical assistance model (involving reliance on education and information as the primary means of achieving civil rights compliance, to the relative or even total exclusion of traditional enforcement); evidence-based decisionmaking (reflecting the need for statistical data in evaluating all programs and activities); cost-effectiveness (embodying the notion that economic impact on a variety of parties should be a primary determinant of program value, even in civil rights or social policy areas); intergovernmental coordination (the recognition that all important objectives cut across program and agency lines); and budgetary constraint (the realization that for the foreseeable future federal and state spending must be sharply curtailed).

NCD's 2002 *Progress Report* contains the following major findings and recommendations:

Disability Statistics and Research

Findings—The measures taken over the past year to improve the relevance and reliability of disability data utilized and disseminated by the Federal Government are encouraging. The report finds that existing cost-benefit assessment research models do not take a number of key factors sufficiently into account, including economic benefits to individuals, nonmonetary costs and benefits, and the net results, particularly over the longer term, of cross-agency cost-shifting. The report finds that no widely accepted methodologies exist for reliably measuring the full impact of accessibility policies on the out-of-pocket and transfer payment costs associated with disability, and on the economic gains associated with enhanced opportunity that accessible architecture, transportation and communications afford.

Recommendations—High-quality research yielding reliable demographic and economic data needs to be a central priority of the NFI, not as an alternative to action but as a guiding force for the major policy changes already under way. People with disabilities should be given expanded opportunities for input into the research agenda. Data elements used in "scoring" legislative proposals for their fiscal impact should be expanded, and new techniques for measuring tangible and intangible impacts of programs and expenditures should be developed.

Civil Rights

Findings—The greatest achievement of the year was the inclusion of access to the polls and of a secret ballot for people with disabilities in the new national voting legislation. In other areas such as judicial interpretation of the Americans with Disabilities Act (ADA), the past year has brought further losses and narrowing of civil rights. Among other things, in the past year the Supreme Court has created a new defense (threat-to-self) that employers can use to avoid the employment-related requirements of ADA. The Supreme Court has also ruled that even where reasonable

obligations in employment are required, any seniority system can take precedence, so far as job assignments are concerned, if workers without disabilities relied upon it for their expectations of work. We note the general pattern of decisions stripping individuals of the right to privately enforce ADA and other civil rights laws.

Recommendations—We applaud the new national voting legislation and note that implementation of the law will depend upon the financial resources and the level of commitment that follow. In relation to the Supreme Court's recent and negative impact on ADA, NCD recommends that the Federal Government, as increasingly the only entity with the power to enforce the law and vindicate individual rights, must incorporate vigorous enforcement into a broad-based strategy that includes education and technical assistance but does not shrink from enforcement in those cases where noncompliance arises from more than lack of information. In a related connection, because the administration has begun to vet proposed social policy and even civil rights regulations by their projected economic impact on small business and other entities, NCD recommends that the administration clarify the role of such potential costs in the area of civil rights. Existing defenses in ADA and other laws are adequate to prevent undue expense to any particular entity.

Education

Findings—Written against the backdrop of historic change in the nation's education system. The chapter begins with lengthy analyses of the No Child Left Behind Act (NCLB) as it bears upon students with disabilities, and of the report of the National Commission on Excellence in Special Education. With reauthorization of the Individuals with Disabilities Education Act (IDEA) scheduled for 2003, these analyses highlight areas in which NCLB and the report either fail to address issues of great concern to students with disabilities or recommend policies (such as restriction of parental due process rights and after-the-fact evaluation of individualized education plans) that we believe threaten the ability of IDEA to continue as an effective tool for preparing students with disabilities in mainstream settings for full participation in society as adults.

Recommendations—IDEA reauthorization should be designed to achieve an effective synthesis of the old and the new and include input to Congress from a broad range of voices including students and former students with disabilities who have benefitted from due process and other controversial procedures surrounding the individualized education plan process; unambiguous requirements for nondiscrimination by school choice; private and charter schools that receive federal education funding; elimination of barriers to the ability of funds to follow students; and clarification of exactly how new testing regimens can effectively and fairly recognize the role of reasonable accommodations for students with disabilities.

Health Care

Findings—Addresses what is perhaps the most tumultuous area of national social and economic policy. The report also examines the implications for people with disabilities of drastic cutbacks of Medicaid by the states, including the implications of such cuts for implementation of the work incentive provisions of the Ticket to Work program. We reiterate basic recommendations for how systemic health-care reform can be done in ways that ensure equal access to persons with disabilities, noting for example the need for Medicare prescription drug legislation to bear in mind the inclusion under Medicaid of many people with disabilities under the age of 65, often with unique, highly individualized needs.

Recommendations—NCD offers basic recommendations for how systemic health-care reform can be done in ways that ensure equal access to persons with disabilities, noting for example the need for Medicare prescription drug legislation to bear in mind the inclusion under Medicaid of many people with disabilities under the age of 65, often with unique, highly individualized needs. NCD also recommends that the severity of this risk be urgently investigated and that Congress consider a number of measures for preventing its occurrence.

Long-Term Services and Supports

Findings—Concentrates on the crisis in long-term care facing our nation as the population with disabilities grows and converges with the rapidly increasing demographic composed of older persons. Taking the Supreme Court's *Olmstead* decision and the President's NFI as its point of departure, the chapter describes a variety of cross-programmatic, multi-agency and intergovernmental coordination issues that must be confronted if the goal of minimizing unnecessary and costly institutionalization is to be achieved. These issues include funding for personal assistance services in the home but extend far beyond this to include transportation, housing, assistive technology and others. We find that mechanisms for achieving the requisite coordination do not now exist, or if they exist are not widely in use. A high-level planning mechanism is needed for coordinating and for ensuring accountability in the *Olmstead*-related activities of a number of federal agencies and programs.

Recommendations—NCD recommends that the Office of Management and Budget and the Congressional Budget Office work together to develop new accounting techniques for scoring the overall effects of multi-agency, cross-programmatic initiatives such as *Olmstead*. Because the effective provision of home- and community-based alternatives to nursing homes for America's at-risk citizens will ultimately require the full partnership of the public and private sectors, NCD also recommends that Congress hold hearings on a range of possible incentives for creation of long-term care insurance coverage from the private sector that will be oriented toward facilitating community living rather than institutional care.

Youth

Findings—Focuses on programs designed specifically to affect youth and on the importance of input to policy from youth on programs that affect their lives. First the report considers school-to-work transition. Effective transition has been frustratingly elusive for many years. This year, the simultaneous reauthorization of IDEA and the Federal Rehabilitation Act creates the unique

opportunity to incorporate the identical transition language in each law. In this way, disputes and cost-shifting over transition between these two service systems based on variations in their governing laws can be eliminated.

Recommendations—Recommendations are also made for cross-budgeting experiments whereby transition services would be funded by grants or appropriations to education-rehabilitation partnerships, with availability of continued funding and accountability jointly and inseparably borne by both.

Employment

Findings—Begins with a discussion of experience during the first year of implementation of the Ticket to Work and Work Incentives Improvement Act (TTWWIIA). NCD notes certain concerns revealed by reported first-year experiences, including inconsistencies between the Act and the underlying Social Security Act that create interpretive uncertainties, and provisions of the Ticket to Work program that in themselves are so complex that they may prevent individuals with disabilities from having the confidence needed to enter employment. Of equal concern, NCD finds that the type of Medicaid cutbacks being pursued by many states (including curtailment of the discretionary Medicaid buy-in programs that were established under the Ticket law to enable Social Security Income recipients to retain health insurance benefits after returning to work) may seriously thwart the efficacy of the new law.

Recommendations—NCD recommends that the Administration and Congress speedily address the question of whether Medicaid cuts are jeopardizing the success of work incentive provisions in TTWWIIA aimed at preserving health insurance for Medicaid recipients who return to work, and if so to devise means for states to fully participate. The forthcoming reauthorization of the Rehabilitation Act is also important, and NCD recommends that Congress address the role of labor market and other pertinent data in the operation of the federal-state vocational rehabilitation system for individuals with disabilities. We also recommend that Congress enact provisions

ensuring that relevant and systematically obtained labor market data will be used by the vocational rehabilitation system in determining the training, placement and service priorities these agencies pursue.

Welfare Reform

Findings—Addresses issues raised by the forthcoming reauthorization of the welfare reform legislation of 1996. New restrictions on the permissibility of rehabilitation services for meeting work requirements have been proposed by the administration. NCD expresses concern that these will leave inadequate time for recipients with disabilities to obtain the services they need to enter or return to work. NCD is likewise concerned that recipients with disabilities or recipients with caregiver responsibilities for people with disabilities will be penalized by loss of benefits for failure to find work, but that in many cases this failure will be the result, not of any lack of effort or motivation on their part, but of the unavailability of support services, assistive technology, accessible transportation or specialized childcare resources that they need.

Recommendations—NCD makes recommendations for addressing these needs (including the need for mandatory linkages between welfare reform and vocational rehabilitation agencies), as well as for addressing the long-term health insurance needs of those who because of illness or disability are uninsurable in the private sector. Finally, because there are some people who, whether or not eligible for Temporary Assistance for Needy Families, may qualify for Social Security Disability Insurance or Supplemental Security Income (SSI), NCD recommends review of all potentially relevant cases for these programs before cessation of benefits occurs.

Housing

Findings—Concerns itself primarily with the draft five-year strategic plan issued by the Department of Housing and Urban Development (HUD) in November 2002. While expressing its continuing appreciation for HUD's responsiveness to NCD recommendations and its openness to

dialog on these recommendations, the report finds serious shortcomings in the plan, especially in its failure to deal with key housing accessibility and affordability issues and in its apparent lack of analysis concerning some of the disability-related issues that it does address. NCD calls upon HUD to develop clear and precise plans for gathering baseline data, evaluating obstacles and postulating numerical and qualitative goals for accessible and affordable housing in this country.

Recommendations—NCD suggests the need to establish goals of national policy. It should be the goal of national policy to so enhance the amount, variety and dissemination of accessible housing as to minimize or eliminate the disparities in cost and supply currently faced by people with disabilities or by people who wish to make their homes welcoming to people with disabilities. More broadly, the report suggests that HUD needs to adopt a longer-term vision that addresses the accessible housing needs of an aging population over the next generation and that reflects some attempts to begin a national dialog over where the impetus and resources for the creation of the necessary housing stock can be found.

Transportation

Findings—Notes the profound changes in air transportation that have continued during the past year and congratulates the Transportation Security Administration for its attention to disability issues and outreach to travelers with disabilities. Concerns continue to be expressed about the availability of services and accommodations in airports during embarkation and disembarkation phases of trips.

Recommendations—NCD recommends that the Department of Transportation clarify the allocation of responsibility among carriers, airport operators and contract services providers for a variety of services and accommodations. Because changes in technology also require updated interpretation of the Air Carrier Access Act and new assessments of the relationship between its and ADA's jurisdiction, NCD recommends that the Departments of Justice and Transportation clarify which law applies to the accessibility of airport ticketing machines and other

technological enhancements. In terms of heightened security issues, the report makes a number of recommendations aimed at ensuring that transportation-system safety and accessibility concerns of persons with disabilities will be covered by the transportation legislation and not left solely to ADA. With our growing recognition of the role played by accessibility and by pedestrian safety in the ability of people with disabilities to live in their communities safely and independently, NCD also recommends that the reauthorization of the Transportation Act strengthen the resources available for, and the requirements applicable to, incorporation of these principles and of suitable consumer input into the design of all federally supported transit projects and into the design of projects that will utilize transit as part of their infrastructure.

Assistive Technology and Telecommunications

Findings—Briefly reviews the role of assistive technology under the NFI. Progress under Section 508 of the Rehabilitation Act was reviewed, a year and a half after it went into effect. Major progress is visible in a number of areas, particularly in the consciousness of Web accessibility issues. But problems have emerged, including delays in implementation of certain provisions and a continuing failure to collect key data that would shed light on the efficacy of the law. With Section 508 due for reauthorization as part of the Rehabilitation Act this year, the Department of Justice's biannual report on Section 508 to the President and Congress, also due this year, is particularly timely. NCD also notes that the E-Government Act represents a watershed in federal information management, providing an important endorsement for the principles of Section 508. Finally, NCD addresses the Federal Communications Commission (FCC), one of the most important federal agencies for people with disabilities. Its role and activities in telecommunications accessibility, hearing aid and cell phone compatibility, accessibility of computer networks in schools and libraries, and other areas are discussed. NCD notes a perceived lack of movement on the FCC's part regarding disability civil rights issues and community fears that regulatory reform will be used to curtail existing protections. Recommendations are made for a major change of direction on the FCC's part, including the following: that the FCC reaffirm its commitment to the principle that economic deregulation and

civil rights enforcement are separate issues; that the FCC rethink its apparent inclination to reduce the scope of telecommunications access rights under Section 255 of the Telecommunications Act; and that the FCC complete action to require that schools and libraries receiving telecommunications subsidies under the E-Rate program ensure the accessibility of the technology and services they offer.

Recommendations—On the basis of its review of the role of assistive technology under the NFI, the report makes bold recommendations for research, not on the barriers to technology access embodied in current law, but on the potential benefits to society that could realistically be expected to result over measurable periods from intensive utilization of assistive and accessible technology. In terms of Section 508, NCD recommends that the Department of Justice expand the scope of its report to provide Congress and the Administration with more of the crucial information they will need. In terms of the FCC, NCD makes the following recommendations for a major change of direction on the FCC's part: that the FCC reaffirm its commitment to the principle that economic deregulation and civil rights enforcement are separate issues; that the FCC rethink its apparent inclination to reduce the scope of telecommunications access rights under Section 255 of the Telecommunications Act; and that the FCC complete action to require that schools and libraries receiving telecommunications subsidies under the E-Rate program ensure the accessibility of the technology and services they offer.

International Issues

Findings—Begins with the crucial recollection that in matters of disability rights as much as in other spheres, our connection with and impact upon the rest of the world is complex and growing, but that in this area perhaps more than in any other it is our example and leadership that account for our influence. While we have many ways of influencing other countries for good, it has primarily been through the respect they garnered that our disability rights laws have had such a profound effect as models in many countries.

Recommendations—The report also notes the long-standing role of the NCD in advising the State Department on international policy issues. On this basis, the report emphasizes the importance of including people with disabilities, and their insights and concerns, in our international development programs. Beyond this, the existence of legal requirements for such incorporation is noted. In the area of international treaties, support is expressed for the UN Convention on the Rights of Persons with Disabilities, and strong U.S. support is urged.

Homeland Security

Findings—Concerns itself with the implications for disability civil rights of the amalgamation of many diverse agencies and programs into the new department. The decisions this department makes, the priority it accords to civil rights and the methods it adopts to ensure uniformity in the ways agencies handle their disability-related responsibilities are likely to be established in the early days and be difficult to change if not set on the right course at the outset. NCD offers its assistance in helping the department to establish policies and practices in these areas.

Recommendations—Emergency preparedness planning around the country presents many issues relating to the inclusion of people with disabilities. All too often a sense of urgency leads to the legitimate concerns of this sector of the population being swept aside. Yet in areas ranging from the accessibility of emergency information to the evacuation plans for high-rise buildings, great urgency surrounds the need for preparedness planning to be done inclusively. The report cannot make detailed recommendations, given the variety of issues already brought to our attention. Instead, we give several examples of effective planning and strive to create awareness and discussion of the issues, as part of the evolving national response to the threats that all too tragically characterize our age.

PART I

Introduction: Major Trends

This annual progress report deals with many issues, programs and laws. While each of these are addressed with specificity, the overarching patterns and general trends that link them together must also be identified. This introduction therefore describes these recurrent themes or major trends, in order to create a framework for the discussion that follows in the next 13 chapters.

1. THE MAINSTREAMING OF DISABILITY ISSUES

One pattern evident for some time became even more noticeable and important this year. Increasingly, issues of disability policy cannot be confronted in isolation from a host of questions facing the entire society. The growing interaction among disability and other public policy concerns results in part from fuller participation of Americans with disabilities in mainstream institutions, but this interconnectedness of issues creates complications unknown to policymakers and advocates of an earlier day.

Two examples from 2002 legal developments illustrate this point. First, Supreme Court decisions that restrict the right of people with disabilities to enforce the Americans with Disabilities Act (ADA) by suits against state government are based on the Court's interpretation of the Eleventh Amendment to the Constitution. As such, these decisions arise from a jurisprudence that affects the enforceability of many federal laws, including but hardly limited to those establishing civil rights for people with disabilities. Their impact on people with disabilities being only one illustration, these decisions may have far-reaching consequences in redefining the understanding of federalism in our nation.

Second, debate over the forthcoming reauthorization of the Individuals with Disabilities Education Act (IDEA) cannot be conducted without reference to the broad-based educational goals and policies of our nation, as recently embodied in the No Child Left Behind Act (NCLB).

Nor can IDEA be amended without attention to likely developments in the areas of school choice and state autonomy, which affect all of America's children.

Through convergence of a number of legal requirements and social trends, services of all kinds are being provided in integrated environments, from the public school to the managed care organization. As a result, decisions about how and what services should be provided to people with disabilities could not be made without reference to the overall structure of these programs. Equally, decisions about the operation of these programs and services can no longer be made without reference to the fact that people with disabilities will be using them.

Technology has also contributed significantly to merging mainstream and disability concerns. Under these conditions, where entities and institutions that care or know little about disability are nevertheless obliged to take it into account in their decisionmaking, and in an environment where even decisions bearing specifically on people with disabilities often have major and far-flung implications, we can hardly be surprised at the growing politicization of disability policy issues and rights.

2. THE RISE OF TECHNICAL ASSISTANCE

Over recent years, the Federal Government has placed increasing reliance on technical assistance as the means for increasing participation in mainstream society for people with disabilities, and as the means for enabling a variety of institutions and entities to accommodate these citizens.

The Administration has emphasized technical assistance and provision of informational and educational resources for people with disabilities and for the public at large. Recent examples of this approach include the New Freedom Initiative's (NFI) emphasis on coordinated, interagency strategies; establishing and strengthening disability-oriented offices within the Department of Labor and the Department of Health and Human Services (HHS); and creation of centralized informational Web sites such as http://www.disabilityinfo.gov and http://www.firstgov.gov.

Productive as these efforts are, they can all too easily be seen as an alternative, rather than an adjunct, to civil rights enforcement. A series of civil rights monitoring reports issued by the National Council on Disability (NCD) over the past three years have documented persistent failures of civil rights enforcement by administrations of both parties. This year, a 10-year retrospective study by the U.S. Commission on Civil Rights put these issues in a broader context.[1] While education and information are invaluable in facilitating responsible behavior by most people, the inescapable truth remains that in some instances, only requirements of the law, enforceable when not voluntarily complied with, can bring about nondiscriminatory and inclusive practices. As we have learned in so many other areas of life, without meaningful legal sanctions, all too many people will fail to uphold the standards society expects, no matter how often or how well they are informed of those expectations. The test for public policy is to develop methods that strike a correct balance between enforcement and technical assistance.

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[1]Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act (National Council on Disability 2000) (currently available at http://www.ncd.gov/newsroom/publications/promises_1.html#main); Back to School on Civil Rights (NCD 2000) (currently available at http://www.ncd.gov/newsroom/publications/backtoschool_1.html); Enforcing the Civil Rights of Air Travelers with Disabilities: Recommendations for the Department of Transportation and Congress (NCD 1999) (currently available at http://www.ncd.gov/newsroom/publications/acaa.html); The Accessible Future (NCD 2001) (currently available at http://www.ncd.gov/newsroom/publications/accessiblefuture.html); and Reconstructing Fair Housing (NCD 2001) (currently available at http://www.ncd.gov/newsroom/publications/fairhousing.html).

An additional civil rights monitoring report on Section 504 of the Rehabilitation Act is scheduled for publication in the first quarter of 2003.

For further perspective, see the U.S. Commission on Civil Rights report Ten-Year Check-Up: Have Federal Agencies Responded to Civil Rights Recommendations? Volume I: A Blueprint for Civil Rights Enforcement (September 2002) (currently available at http://www.usccr.gov/pubs/10yr02/vol1/main.htm).

3. EVIDENCE-BASED DECISIONMAKING

Society has often made its most fundamental decisions on the basis of faith or of shared values that neither require nor admit of empirical verification. For example, we differ not on whether people with disabilities should be educated, empowered to work and assisted to live productive lives, but on what the best methods are for bringing these goals about. In choosing among policy options, evidence (including statistical data) is becoming increasingly important, both as tools for defining issues and as a means for evaluating the efficacy of various strategies.

The growing reliance on evidence makes sense, but only to the extent that data are correct and actually prove what they purport to show. Where decisions about issues ranging from the value of medical technology to the effectiveness of educational interventions are made on the basis of statistical data, great sensitivity in formulating research designs will be required if accurate data are to be mined.

A classic example relates to the phenomenon of "abandonment" of assistive technology (AT) by persons with disabilities. Research has been cited for having disclosed high rates of abandonment,[2] but unless these findings are further analyzed they can be seriously misleading. In what proportion of instances is this so-called abandonment in fact the result of a change in disability status, perhaps even medical recovery? What proportion can be attributed to the user's changing job requirements or personal circumstances, to a failure to prescribe the correct device to begin with, or to a lack of training and technical support in the use of the equipment? To what extent should the useful life of assistive devices be compared with the life cycle for other devices used by people without disabilities? Until or unless questions such as these are answered, the stark notion of abandonment will remain more emotionally evocative than pragmatically useful.

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[2]e.g., Survey of Rehabilitation Technology Services in Vocational Rehabilitation Agencies, in General Report of Findings (Rehabilitation Engineering Research Center on Rehabilitation Technology Applications in Vocational Rehabilitation, 1993).

4. COST-BENEFIT ANALYSIS

An increasingly important branch of evidence-based policymaking is the use of cost-benefit analysis to evaluate various laws and practices. Several factors differentiate recent approaches to such analysis from those traditionally used by Congress to estimate the impact of proposed legislation.

Too often only those costs and benefits that can be readily aggregated are considered. Thus, if a proposed regulation (including potentially a civil rights regulation) potentially imposes financial costs on government or private entities, data concerning the extent of such costs would quickly be made available by the affected parties.

In an effort to minimize the burdens borne by small entities, regulatory flexibility and other impact statements are now required in a number of areas that might traditionally have been judged on other grounds. For example, civil rights have long been thought too important to rise or fall on cost alone, particularly when the methodology for deriving such estimates is often unverifiable and where no parallel resources exist for measuring the economic benefits. If cost-benefit analysis is to emerge as a reliable source of information, its methodology, its fairness and its balance must be greatly improved.

5. INTERGOVERNMENTAL COORDINATION

A corollary to the increasing complexity of policymaking is the involvement of a growing number of partners in implementation of any major public policy initiatives. As an interagency, cross-governmental undertaking, the NFI powerfully demonstrates this point.

Yet as our need for coordination grows, our tools for achieving it remain inadequate. From the standpoint of planning, budgeting, implementing and evaluating programs in the disability policy arena, we continue to rely on narrowly targeted programs that operate within limited jurisdictions

in attempting to address problems that transcend and confound traditional jurisdictional lines or statutory demarcations.

Means must be found for making and carrying out policy that are equal in scope to the problems being addressed or the goals being pursued. The year 2003 offers a unique opportunity for beginning this new era in policymaking. Several major disability-related laws, including IDEA, Temporary Assistance for Needy Families (TANF), Transportation Equity Act for the 21st Century (TEA-21), Head Start, the Higher Education Act, the Rehabilitation Act and the Assistive Technology Act all are due for reauthorization this year. Never in recent history have so many seminal and closely intertwined programs been on the congressional agenda at the same time. The opportunity for thoroughgoing coordination and for creating a cohesive approach that this coincidence of timing offers must not be missed.

6. BUDGETARY CONSTRAINT

For the foreseeable future, what is termed discretionary spending at federal and state levels is likely to be under severe pressure. While new categories of spending at the federal level, including homeland security, make it difficult to determine whether or not what is called discretionary domestic spending has risen, fallen or remained flat, as far as the concerns and priorities of the disability community are concerned, a growing number of policymakers are coming to view these concerns as necessarily subordinate to other costs. As such, even investments in infrastructure or civil rights enforcement may be viewed as among the most discretionary of discretionary costs.

Reflexive budget cutting, though an understandable reaction to short-term crises, is all too likely under current circumstances, particularly at the state level. Under such circumstances, the demand for hard choices and for the establishment of priorities can all too easily be taken as nothing more than the special pleading of another interest group.

But public officials, however beleaguered, cannot be allowed to evade responsibility for the long-term implications of their decisions.

Disability Statistics and Research

1. STATISTICS

In today's evidence-based policy environment, the ways that disability-related data are collected and used have come under growing scrutiny. In our 2000–2001 annual progress report,[3] NCD detailed concerns about employment data in particular and expressed the twin hopes that methods for its collection are improved and that existing suspect data not be disseminated under government aegis. The report offered recommendations for developing effective data-gathering tools and techniques.

Spearheaded by the Bureau of the Census and the Bureau of Labor Statistics, work has continued on the perfection of questions and methodology, but as of this writing the results of these efforts have not yet been presented. NCD continues to offer its assistance in evaluating proposals, in bringing persons with disabilities into the process and in field-testing new questions and techniques. We note that with the inclusion of disability-demographics questions in the March Supplement to the Census Bureau's Current Population Series survey, new urgency and opportunity attach to this effort.

Because of the critical need for reliable and comprehensive Census data regarding individuals with disabilities, NCD recommends that Congress legislatively require an official and accurate enumeration of Americans with disabilities through the decennial census, as well as through related national census-like efforts (e.g., American Community Survey).

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[3]National Disability Policy: A Progress Report, December 2000–December 2001 (National Council on Disability, July 2002) (currently available at http://www.ncd.gov/newsroom/publications/progressreport_07-26-02.html).

Nor is employment policy the only area in which statistics and evidence-based decisionmaking are coming to play a larger role. An increasing number of government agencies are now involved in the disability data collection process and in making decisions predicated upon assumptions regarding the number and status of Americans with disabilities. From the Centers for Disease Control and Prevention (through its Healthy People 2010 initiative and its state-by-state disability prevalence studies),[4] to the Food and Drug Administration (through its role in evaluating high- and low-incidence medical devices),[5] the venues and complexity of decisionmaking and priority-setting demand quality data as they never have before.

Because of the variety of entities and data sources involved, NCD recommends that the NFI should make improvement of data collection a high priority.

2. RESEARCH

(a) THE RESEARCH AGENDA

In its reports over the years, NCD has consistently advocated for a broad-based research agenda. In this connection, we wish to acknowledge the work of the Interagency Subcommittee on Disability Statistics (ISDS) and its parent Interagency Committee on Disability Research (ICDR). Given the potentially enormous range of issues worthy of statistical and analytical research, NCD recommends that these entities seek input from the disability community regarding their most pressing concerns.

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[4]http://www.cdc.gov/ncbddd/dh/schp.htm

[5]107th Cong., HR 5651, The Medical Device User Fee and Modernization Act of 2002. Added as PL 107-250.

NCD also recommends that the new International Classification of Function (ICF) (discussed at the ISDS meeting of December 11, 2002)[6] be evaluated for its applicability to laws and programs in the United States, and for its potential impact on the disability research agenda. ICF's approach suggests the need for wholly new types of research. Adoption by much of the world of the ICF signals a turning away from organic- or deficit-based models of disability in favor of models of function that link the individual and the environment in new and direct ways, that in effect allow the presence and extent of a disability to be determined by the nature of the physical, communication or social environment in which the individual functions.

Such a model holds out intriguing and compelling possibilities. By way of disease prevention, it suggests the need to go beyond the traditional boundaries of causation and treatment that are considered medical, and to examine a variety of interactions between individual, environment and community in order to better understand means for enhancing function and participation. Similarly, in areas such as rehabilitation, education and employment, adoption of the ICF approach suggests the need to include research not only into how to make various environments more accessible to people with disabilities, but also into how the functional and benefits and other results of such environmental modifications can be identified and measured. Researchers will, however, need to ensure that ICF items are valid, reliable and useful to policymakers and researchers.

Research into the measurable impact of environmental modifications on the economic and opportunity costs of disability is therefore warranted. Put broadly, the disability research agenda needs to include systematic assessment of the cost-benefit equation attaching to universal design in various settings.

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[6]Minutes of Interagency Subcommittee on Disability Statistics (ISDS) meeting of December 11, 2002 (currently available through http://www.ncddr.org/icdr/isds).

Particularly when linked to the aging of the population, such research could help establish the business case for accessible design in a number of product areas. Yet industry cannot necessarily be expected to conduct such research on its own.

To help fill this need, NCD is undertaking research into barriers to and costs associated with universal design,[7] but models for capturing the long-term benefits of such practices do not yet command broad-based consensus. For example, it is plausible that if all the homes in which a population of senior citizens lived were equipped with certain accessibility and safety features (e.g., nonslip flooring surfaces and bathtub grab bars), significant reductions in hospital costs attributable to falls might be achieved, or admission to nursing homes delayed. As one small study has already found, provision of accessible telephone equipment to a sample of people with disabilities could result in increased telephone usage of sufficient scope to yield revenues to the carrier exceeding the costs of the AT.[8]

Accordingly, NCD recommends that in prioritizing disability research the Administration also fundamentally assess current research agendas to make sure that the potential benefits of a wide variety of environmental and community-design strategies can be fully taken into account in the formulation of public policy, and to ensure that suitable methodologies for gathering such information are developed and validated.

(b) QUALITY OF LIFE

If data from various sources can be combined in ways that show new relationships among various demographic, social and economic findings, important new insights into the comparative

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[7]NCD Presolicitation Announcement of Universal Design RFP (NCD Bull. November 2002) http://www.ncd.gov/newsroom/bulletins/b1102.html.

[8]e.g., Effectiveness of Assistive Technology and Environmental Interventions in Maintaining Independence and Reducing Home Care Costs for the Frail Elderly: a Randomized Controlled Trial, by William Mann et al., 8 Archives of Family Medicine 210–17 (1999).

quality of life for people with and without disabilities can begin to emerge. Preliminary analysis of several data sets in conjunction has begun to yield some provocative evidence of clustering, which begins to shed new light on the relationships between location, age, disability, employment and education, and which demands further attention.

In deriving these data, NCD looked to several national-level sets of data for some quality-of-life indicators for Americans with disabilities, such as the Census 2000 data system and the special education child count data system. Specifically, NCD looked at the Census 2000 Summary File 3 (SF3), which incorporates a set of products that include disability data involving detailed tables, quick tables and thematic maps. For detailed tables available from SF3, "disability" is reported by age, sex, employment status and poverty in the detailed tables labeled P40–P41, P119–P126 and PCT26–PCT34.

The thematic maps, available from SF3, display population density data with a color scheme representing the percentage of persons with a disability within three specific age groups. According to the SF3 tables, nationally, 17.6 percent of Americans with disabilities live at or below the poverty level, while 10.6 percent of Americans without disabilities live at or below that level. This national average may obscure even greater disparities from state to state. According to the SF3 tables, when looking state by state, poverty estimates for Americans with disabilities range from 11.6 percent to 25.1 percent.

According to the SF3 detailed tables, nationally, 43.4 percent of Americans with disabilities ages 21–64 were identified as "not employed," while only 22.8 percent of Americans without disabilities (approximately half as many) were identified as not employed. In the 41 states whose data were included in the SF3 flow of information for this table, the percentage of Americans with disabilities identified as "not employed" ranged from 35.0 to 59.6 percent.

When the state-by-state poverty and the not-employed data are plotted on a map, a visual inspection reveals (a) a clustering of southeastern states whose average poverty rates among

Americans with disabilities exceeds the national average and (b) a clustering of southeastern states whose average not-employed rate exceeds the national average.

Turning to the education data, the 23rd Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (2002) provides another national data system for consideration. Table AD1, in particular, provides outcome indicators for "Basis of exiting" from special education. An analysis of the data related to the indicator referred to as "dropped out" was reviewed. It shows that state-by-state dropout rates also vary widely, ranging from 4.5 percent to 28.2 percent. In addition, Table I-2 reports that the dropout rates for students age 14 and older with disabilities by race and ethnicity were 44.0 percent for American Indians/Alaskan Natives, 18.8 percent for Asian/Pacific Islanders, 33.7 percent for African Americans, 32.3 percent for Hispanic Americans and 26.9 percent for Caucasians.

Available data highlight the persistence of higher poverty rates among persons with disabilities than among the general public in all three major age groupings—children up to age 16, working ages 16–64 and senior citizens 65 and over.[9] Among persons with disabilities of working age, some would regard the higher incidence of poverty as no mystery, given the statistical correlations between poverty and such variables as higher levels of unemployment and unmarried status and lower levels of educational attainment, all of which characterize the disability demographic and are generally associated with poverty.

But whether these variables entirely account for the poverty level, let alone what accounts for these underlying differences, remains far from certain.

If data were adjusted to control for the statistical significance of the four variables of age, employment status, marital status and educational level, would people with disabilities still be poorer than other Americans? If so, their possession of less discretionary income and resources (including limitations imposed on their resources by various means-tested public programs aimed

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[9]NCD 2002, Internal Document, Quality-of-Life Data Tables.

at helping people with disabilities enter or return to work) could be a factor in explaining why. Hence one potentially fruitful direction for further research into the causes of lesser economic attainment by persons with disabilities is the uncompensated costs of living with a disability. NCD recommends that research into these costs of living with a disability should likewise be made part of the national agenda, with a view both to documenting their nature and extent and to determining whether out-of-pocket costs of disability (such as the need for various forms of personal assistance) could be reduced by changes in the design of products, environments or communities.

3. SCORING

The point at which statistics and research bear practical fruit is in the cost estimates and related analyses of proposed federal legislation carried out by the Congressional Budget Office (CBO). In the nearly 30 years since its creation, the CBO has earned a reputation for nonpartisanship and objectivity. While the quality of CBO's work is unquestioned, the adequacy of the statutory framework governing its evaluation of certain disability policy proposals may be open to question.

Three basic problems must be noted here. First, many of the benefits of full participation in society are intangible. They cannot be measured in dollars cost or saved, nor should they be, any more than the costs of national defense or of civil rights.

In this connection, even when economic impact data may exist, people with disabilities are not "private entities" of the sort about which economic impact data can readily be collected. Many of the practical benefits foreseen for disability-related proposals appear all too conjectural under the microscope of current analytical techniques. Costs and benefits to government, industry and other identifiable institutions, not to individuals, inevitably take center stage in any cost-benefit analysis, including many of those conducted by the CBO, which, like any other scoring agency, can utilize only the criteria established by law and the data available.

The second major problem with scoring has to do with when programs are scored. Once a program or service system is in place, occasion does not ordinarily arise for formally re-evaluating its costs and benefits unless amendments are proposed, Government Accounting Office (GAO) studies are conducted or special commissions are appointed. Thus, potentially ineffective or even destructive policies, such as those which in the aggregate are believed to direct a far higher proportion of resources to institutional care than to community- and home-based services, escape the opprobrium they deserve.

Third and finally, many measures in disability policy are likely to have positive revenue implications for government, but these measures are achievable only after a number of years and only through increased up-front expenditure. Too often, the existence of a long timeframe is confused in the public mind with the hypothetical or conjectural nature of the benefits to be achieved in the future. Equally problematic, the budget process does not create opportunity or incentive for one agency or program to incur expenses today so that another can reap greater savings tomorrow.

For all these reasons, NCD recommends that the CBO undertake a review of these issues, including the extent to which it can seek input directly from individuals with disabilities on issues of concern to their lives, the extent to which nonfiscal impacts can be captured by existing scoring assumptions and methodologies, the feasibility of rescoring selected existing programs where appropriate, and the capacity of current techniques to reliably take longer-term forecasts and extrapolations and cross-agency budget relationships into account. The CBO should report to Congress and to the nation on its findings at the earliest possible time, and should be given the resources needed to gather the expertise it will need to authoritatively answer these key questions in forming public policy.

Civil Rights

1. ADA

(a) THE COURTS

In a series of papers this year entitled "Righting the ADA,"[10] NCD has continued to report on a succession of Supreme Court decisions narrowing the rights of citizens with disabilities under ADA. In 2002, the cavalcade of anti–ability rights decisions reviewed in last year's report has been joined by rulings

- barring the award of punitive damages in cases brought under Title II of ADA (or under Section 504 of the Rehabilitation Act);[11]

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[10]For comprehensive analysis and background, see NCD's ADA Policy Brief Series, which thus far includes four briefs. These Righting the ADA papers are Righting the ADA, Policy Brief No. 1: Introductory Paper: The Americans with Disabilities Act (NCD, October 16, 2002) (currently available at http://www.ncd.gov/newsroom/publications/rightingtheada.html); Policy Brief No. 2: A Carefully Constructed Law (NCD, October 30, 2002) (currently available at http://www.ncd.gov/newsroom/publications/carefullyconstructedlaw.html); Policy Brief No. 3: Significance of the ADA Finding that Some 43 Million Americans Have Disabilities (NCD, November 15, 2002) (currently available at http://www.ncd.gov/newsroom/publications/43million.html); and Policy Brief No. 4: Broad or Narrow Construction of the ADA (NCD, December 16, 2002) (currently available at http://www.ncd.gov/newsroom/publications/broadnarrowconstruction.html). Additional papers dealing with all the issues raised by recent court decisions will be published during 2003.

[11]*Barnes v. Gorman*, 22 S. Ct. 2097 (2002) (currently available at http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&navby=case&vol=000&invol=01-682).

- holding that reassignment of workers or other reasonable accommodations are not required when their provision would violate an established seniority system, even a system unilaterally implemented by an employer without collective bargaining; and[12]
- further narrowing the definition of disability in the workplace.

The two most widely discussed cases deal with employment. In *Toyota v. Williams*,[13] the Court ruled that the company had not violated the law by refusing to accommodate a worker with severe carpal tunnel syndrome. Williams was not considered a person with a disability within the meaning of the law, because she could perform many routine housework tasks at home. This meant she was not "substantially limited" in the major life activity of working.

To understand how the Supreme Court could draw conclusions about someone's ability to work based on what they can do in nonwork situations, a new and disturbing approach adopted by the Court must be addressed. In previous cases, the Court looked directly at whether working was substantially limited by the impairment. In this case, the court did not look directly at working at all but assumed that since the carpal tunnel syndrome did not totally preclude the performance of all routine manual tasks in everyday life, the condition could not constitute a work disability.

Thus, it appears that the Court will look to the impact of the impairment in the workplace in resolving some ADA employment cases but will look to different impacts in deciding other cases. Very few people are likely to have impairments that meet this new test. For example, if a person using a wheelchair is able to move around her home or community, would the Court now rule that mobility-related limitations on her job performance in the workplace do not amount to a major limitation of working since she is able to get around all right at home?

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[12]*US Airways v. Barnett*, 535 US 391, 122 S. Ct. 1516 (2002) (currently available at http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US.navby=case&vol=000&invol=00-1250).

[13]*Toyota Motor Manufacturing (Kentucky) v. Williams*, 534 US 184, 122 S. Ct. 681 (2002) (currently available at http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&navby=case&vol=000&invol=00-1089).

In the other major ADA employment case, *Echazabal v. Chevron*,[14] the Supreme Court was called upon to interpret the "direct threat" language of the law. Prior to this case and based on the statutory language and legislative history of the statute, observers had believed that this language allowed an employer to refuse to hire someone with a disability when doing so would pose a direct and objectively verifiable risk to others.[15] But in upholding Chevron's refusal to give Echazabal a refinery job, the Supreme Court held that the company could deny him the position based on risk to the life and health of the employee himself, which supported expansion of the standard contained in Equal Employment Opportunity Commission regulations. Moreover, the Court held that in making this decision, the employer need not give credence to either the views of the job seeker's physician or the informed consent of the worker. This decision legitimizes reliance on fear and stereotypes as grounds for denying employment to people with disabilities.

In addition to legitimizing the fears and stereotypes of some employers, this decision dramatizes more than any other the major problem confronting Americans with disabilities in the courts. As discussed in section b below, disability discrimination has not been accorded constitutional status. A quarter century ago, the Supreme Court held it illegal to refuse a job to a woman employee based on risk to her health where informed consent existed.[16] But today the Supreme Court says the identical refusal to allow a person with a disability to work raises no issues. Because gender is constitutionally recognized (a so-called "suspect classification"), discrimination against women (or against men) is reviewed with special scrutiny, whereas

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[14]*Chevron USA Inc. v. Echazabal,* 122 S. Ct. 2045 (2002) (currently available at http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=US&navby=case&vol=000&invol=00-1406). Compare the Supreme Court amicus curiae brief filed by NCD (Brief Amicus, Docket 00-1406, February 2002) (currently available at http://www.ncd.gov/newsroom/publications/chevron_amicus.html).

[15]Ironically, in extending the "direct threat" defense under Title I of ADA to dangers to the worker himself or herself, the Supreme Court was upholding a regulation of the Equal Employment Opportunity Commission. Courts are already showing signs of enthusiasm in upholding this new "threat-to-self" defense being pleaded by employers. See, e.g., *Orr v. Wal-mart Stores Inc.*, 297 F. 3d 720 (8th Cir. 2002).

[16]*United Auto Workers v. Johnson Controls,* 499 US 187 (1991).

discrimination against people with disabilities, who have no constitutionally protected status, is governed only by statute. If ADA can be interpreted to allow a given employer practice, then no recourse to the Constitution may be available.

Beyond these decisions themselves, we noted in last year's report an atmosphere of profound fear and uncertainty among Americans with disabilities because of potential or real loss of legal protections. This climate of fear has become more pervasive during 2002 as a result of the continuing trend of court decisions unfavorable to disability rights and of the Federal Government's disinclination to include civil rights enforcement as a major element of the NFI.

In light of the many questions raised by recent Supreme Court decisions, the disability community lives under an atmosphere of legal siege. With few exceptions, court decisions bearing upon their rights and interests are being adversely resolved. When disability rights advocates discuss court decisions today, their focus is rarely on the extension of civil rights but rather on how to prevent or slow further erosion.

Other ADA issues making their way through the courts raise concerns about the ability of the law to accommodate changes in technology and society. Of particular concern here is the question of the applicability of ADA to Web-based services and commerce, and other electronic and information technology (E&IT) used in employment, education or commerce. Several federal court cases this year have dealt with the applicability to the Internet of Title II (local government services) and Title III (public accommodations). Perhaps the most publicized Title III case is a Florida District Court decision holding that ADA does not extend to an airline's Web site.[17] The leading Title II case from the Federal District Court in Georgia is more favorable.[18]This case holds that the Web site of a public transit agency must be accessible to users with disabilities.

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[17]*Access Now v. Southwest Airlines,* 227 F. Supp. 2d 1312 (SD Fla. 2002) (appeal pending).

[18]*Martin v. MARTA,* F. Supp. 2d (ND Ga. October 15, 2002) (currently available at http://www.gand.uscourts.gov/documents/1001cv3255TWTinj.pdf).

Pending NCD's publication of an in-depth analysis of ADA and the Internet, the legal issues surrounding these cases will not be further explored here.

In a positive development, the Supreme Court in *Atkins vs. Virginia* ruled that executions of persons with cognitive disabilities found guilty of a crime are "cruel and unusual punishments" prohibited by the Eighth Amendment. The Court reasoned that it was "not persuaded that the execution of mentally retarded criminals will measurably advance the deterrent or the retributive purpose of the death penalty." The Court also referred to the growing number of states prohibiting the execution of persons with mental retardation as a reflection of society's view that those with cognitive disabilities are less culpable for their offense.

(b) THE CHALLENGE

Faced with a disheartening and deteriorating judicial situation, NCD is issuing a series of studies, Righting the ADA, which set forth the legal and human implications of these decisions, explain to the public and judiciary the background of ADA, and analyze the prospects for reform. Three in this series of policy briefs have been issued thus far.[19] The series of briefs will conclude with a comprehensive report including legislative proposals and options.

Whether these and other efforts can bring about a reduction in apparent judicial antipathy to ADA and disability civil rights, only time will tell. But as suggested above, and as important as the outcome of particular cases, is the overall stance and leadership role taken, or not taken, by the Department of Justice (DOJ). In its law enforcement role, its regulatory functions and its role of informing and educating the courts, DOJ may well occupy the most pivotal position of any institution in our nation for shaping the course of disability civil rights and full inclusion. While the department's efforts in a number of areas warrant commendation and encouragement, we feel compelled to observe reluctantly that in a number of other key areas the progress has thus far fallen short of what might be hoped.

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[19]Note 10, supra.

As indicated in the introduction to this report, a new and different philosophy may be at work in the Administration's implementation of ADA and other civil rights statutes. As opposed to the inadequate, under-resourced and passive approach that marked the previous decade, the current Administration may believe that vigorous civil rights enforcement, through the use of the sanction of the law, is not an effective way of bringing about nondiscriminatory behavior. If this is indeed the Administration's view, we urge its reconsideration.

Even in a time of limited resources and elimination of regulatory burdens on the public and private sector, we do not face an either–or situation in which public education and technical assistance on the one hand are somehow inconsistent with or pitted against vigorous law enforcement on the other. Indeed, we believe that neither can be effective without the other. At this critical time, only a full-spectrum approach can make the best use of scarce resources. To ensure the necessary scope and balance in the federal approach, NCD recommends that the Administration recommit itself to the appropriate use of civil rights enforcement as one technique among those it will use to bring our commitment to equality to fruition.

In this connection, NCD notes with alarm the apparent intention of some to subject civil rights enforcement to a new and ominous form of cost-benefit analysis. A letter written by the Small Business Administration's (SBA) Office of Advocacy to the Architectural and Transportation Barriers Compliance Board (the Access Board) (which the letter repeatedly misidentifies as the "Compliance Board") on September 6, 2002, epitomizes this new approach.[20] In this letter the SBA office urges delay in adoption of a final rule amending the Americans with Disabilities Act Accessibility Guidelines (ADAAG) on the grounds that a number of required regulatory assessments had been made in ways that did not comply with required procedures or were inaccurate. The letter (which is similar to others this office has written to other federal agencies,

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[20]Letter of Thomas M. Sullivan, Chief Counsel for Advocacy, Small Business Administration, to the Architectural and Transportation Barriers Compliance Board (September 6, 2002) (currently available at http://www.sba.gov/advo/laws/comments/atbcb02_0906.html).

protesting their proposed regulations)[21] indicates that the Office of Advocacy is working closely with the Office of Management and Budget (OMB) and DOJ and indicates that more formal measures may have to be taken if the draft final rule is not withdrawn.

NCD is seriously concerned about the approach to ADA, and by implication to other civil rights laws that this protest embodies. ADA provides a number of defenses, including "undue burden" under Title III and "undue hardship" under Title I, for the protection of entities against excessive financial obligations. NCD is aware of no research suggesting either that these defenses are unworkable or that courts or administrative tribunals have in any way narrowed their applicability. Yet a protest such as this cites federal regulations, including executive orders, purporting to shift the analysis from a case-by-case determination to an up-front, global one, predicated upon what must be highly unscientific estimates and subject to no detailed examination or cross-examination as a particular entity's claim of undue burden would be.

NCD questions the wisdom or legal basis for allowing unsubstantiated global cost estimates that impede the adoption of regulations implementing civil rights laws in accordance with statute, or that place a heavy burden of proof and procedural compliance on the agencies acting in fulfillment of their statutory responsibility to adopt regulations. NCD recommends that the OMB clarify its views regarding the applicability of pre-adoption regulatory-burden analyses to civil rights legislation, and to make clear that the defenses available to private entities under ADA should in most circumstances provide ample protection against excessive or burdensome demands.

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[21]Letter of Thomas M. Sullivan, Chief Counsel for Advocacy, Small Business Administration, to the Occupational Safety and Health Administration (October 30, 2002) (currently available at http://www.sba.gov/advo/laws/comments/osha02_1030.html).

2. HATE CRIMES

As we did in last year's report, NCD recommends that Congress adopt legislation extending federal hate crimes protection to a number of groups, including persons with disabilities. NCD believes the needs underlying this recommendation are more imperative than ever.

Although all vulnerable groups (including people with disabilities and the very young or very old) face heightened risks and unique forms of victimization, some of the threats specific to those with disabilities have received far less attention than dangers facing other groups. In the cases of people with disabilities who do not dare report physical abuse or economic exploitation by caregivers, women with disabilities who remain in abusive relationships longer than abused women without disabilities, or victims of street crimes whose assailants are charged with less serious offenses because of prosecutors' perceptions of difficulties associated with winning a conviction, the likelihood, severity or duration of their victimization is determined by disability.[22]

3. GENETIC DISCRIMINATION

In reports dating back to 1996 (including most recently its White Paper on Genetic Discrimination, issued in February 2002),[23] NCD has urged the enactment of strong genetic antidiscrimination legislation ensuring that DNA would not become destiny in matters of employment, insurance or health care. Regrettably, little progress has been made in this regard

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[22]e.g., Flawed FBI Reporting System Undercounts Disability Hate Crimes, by Kathleen Maclay (UC Berkeley Campus Media Relations, December 18, 2002) (currently available at http://www.berkeley.edu/news/media/releases/2002/12/18_crimes4html). Also Prevalence of Abuse of Women with Physical Disabilities, by Me Young et al., 78 Archives of Physical Medicine and Rehabilitation, S34-S38 (1997).

[23]Position Paper on Genetic Discrimination Legislation (National Council on Disability, March 2002) (currently available at http://www.ncd.gov/newsroom/publications/geneticdiscrimination_positionpaper.html). Also Principles for Genetic Discrimination Legislation (NCD, March 2002) (currently available at http://www.ncd.gov/newsroom/publications/geneticdiscrimination_principles.html).

during the past year. Meanwhile, developments have occurred making such legislation all the more urgent and pressing.

NCD's white paper recounts studies demonstrating the widespread occurrence of genetic discrimination suffered by people believed to be at risk for genetic disease. More ominous, the studies document how fear of genetic discrimination leads many people to forego medical testing or even necessary treatment. Genetic discrimination therefore has already resulted in harm, and very probably, in more than a few deaths.

Increasing reliance on newly available sources of genetic information can only make these problems worse. The past year has witnessed the completion of the mapping of the human genome. Moreover, barely a week goes by without media accounts of research findings linking one or another disease or disease predisposition to a particular gene, missing or duplicated chromosome, or other genetic marker. While this research has not yet resulted in major successful interventions in the clinical course of any condition or disease, and while the fine print beneath the headlines usually indicates that the genetic marker in question accounts for only some fairly small percentage of disease instances, new genetic tests continue to proliferate, with the prospect even of home test kits in the offing.

The build-up of data purporting to link genes and health provides increasing rationalization for those who would use putative science to engage in what is known as "adverse selection" (that is, screening people out of insurance or employment on health-risk grounds). Moreover, since genetic information can often be obtained as a byproduct of other permissible tests, many people may be victims of genetic discrimination without ever knowing that such information has been obtained and used.

In a nation that prides itself on its belief in the worth of the individual, what could be more shocking, more objectionable, than a system of laws that countenances life-altering decisions being made about us on the basis of tiny snippets of protein in our cells over which we have no

conceivable control? How does such a situation square with the values of personal responsibility that we invoke?

Hopes for application of ADA to prevent genetic discrimination were dealt a severe blow this year by the Supreme Court's Echazabal decision, noted in section 1a, above. Echazabal involved an individual with a long-standing liver condition seeking a job that would expose him to potential liver toxins, which in the view of the company would pose a "direct threat" to his health. What if instead of an actual liver disease, the employee had a genetic marker regarded as highly predictive of liver disease? Nothing in the Court's decision suggests the outcome would be different if the employer's decision were based on the perceived interaction between a genetic predisposition and environmental hazards. From the law's standpoint, there now seems to be little to distinguish a latent from a chronic condition.

Although many complexities and technical issues surround the crafting of genetic rights legislation, only one bona fide argument against trying appears to exist: namely, that if insurers and employers were prevented from using genetic information in their decisions about who to insure or employ, the costs of insurance and of doing business would increase, resulting in unaffordable insurance for some and a general decline in economic efficiency for all. NCD is aware of no empirical research confirming these predictions, especially in light of the arguably greater costs to society, even to health insurers and employers, of people's foregoing diagnosis or delaying treatment. Thus, against an undocumented claim that the sky will fall is set the basic right, fundamental under any standard of human dignity, to be judged on the basis of one's actions, capabilities and life choices.

Of course, there is no constitutional right to health insurance or to hold a particular job, but as use of genetic screening increases, the time may soon be at hand when the question for people with certain genetic makeups will be not whether they have a right to any particular job, but whether they have any right to work at all.

As genetic screening becomes more accessible, growing numbers of people with suspect genes are likely to appear. When we take into account group insurance decisionmaking based on the genetic endowments of family members (or of nonbiologically related but covered spouses and dependents), soon there will be few of us who are free from the risk of genetic discrimination if anyone cares to look into our cells.

NCD's white paper makes detailed recommendations for remedial legislation. NCD recommends that the new Congress recognize the growing importance of this issue and curb the discriminatory use of genetic information in insurance and employment, while there is still time. Genes are everybody's endowment, and one way or another discrimination based on genetic makeup is everybody's problem.

4. VOTING RIGHTS

NCD congratulates all those involved in enactment of the Help America Vote Act of 2002.[24] Among its reforms, the new law provides authorization for funding to assist states in creating accessible polling places and requires installation of at least one accessible voting machine in each precinct.

For the first time many voters with disabilities look forward to casting their ballots independently and in private. Others who could not access their polling places at all look forward to entering the voting booth for the first time. But after pausing to acknowledge the significance of these reforms and to praise all those involved in bringing them about, we must turn our attention to ensuring that the law proves effective in fulfilling its promise.

In this connection, several areas need to be watched carefully. Despite the fact that the bill provides for federal grants to the states for a number of purposes, the law is generally regarded as weak in enforcement mechanisms. DOJ can seek injunctive relief to stop its violation, and the

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[24]107th Cong., HR 3295, The Help America Vote Act of 2002. Added as PL 107-252.

potential does exist for criminal prosecution for those who conspire to deprive Americans of their vote, but no federal entity has rule-making authority of the kind with which we have become familiar under most other funding programs, and nothing in the law defines as clearly as might be hoped what will constitute compliance in respect to various key provisions.

To provide a baseline for evaluating the success of the Act in enfranchising Americans with disabilities, NCD recommends that the Administration (through the voluntary oversight commission created by the statute, in combination with DOJ, the Federal Elections Commission, HHS or such other entity as may have the resources and the jurisdiction to be of assistance) undertake research during and after the 2004 election campaign aimed at determining whether or not significant numbers of voters with disabilities who might not otherwise have been able to vote were facilitated in doing so by the law, and whether or not significant numbers of persons with disabilities who could not previously do so were enabled to exercise the right of a secret ballot.

Because the discretionary funding formula established for the distribution of federal grants requires continued appropriations, and because of the current budget situation, NCD also fears that the sums authorized for disability access in the states may prove insufficient or prove unavailable, particularly in larger states, poor states or those hard-hit by the economic downturn. NCD is also concerned about the photo-ID requirement. We urge Congress to be alert to these concerns and to ensure that actual appropriations levels are adequate to meet the need.

5. SECTION 504

NCD expects to issue the sixth in its series of major civil rights monitoring reports early in 2003.[25] The report will cover Section 504 of the Rehabilitation Act of 1973, the first major civil rights statute covering persons with disabilities in our nation.

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[25]See the NCD civil rights monitoring reports, Note 1, supra.

In anticipation of this report, NCD has become increasingly concerned with the erosion of consciousness and enforcement surrounding Section 504. As evidenced in court decisions limiting availability of damages to victorious civil rights plaintiffs, the failure of Administration plans to feature many, if any, references to Section 504, and the use of new funding approaches that may narrow the extent to which federally sponsored activities are covered by Section 504, serious concern exists regarding the continued vitality of this historic and effective law.

NCD recommends that DOJ publicly affirm its commitment to the principles and the use of Section 504 as an important instrument for ensuring full access and civil rights for all citizens. In this connection, we also recommend that the Administration revitalize and empower the Interagency Disability Coordinating Council as a major vehicle for the coordination of Section 504 policy and implementation among the numerous federal agencies that must be engaged if the law is to achieve its full potential.

Education

In last year's report, NCD noted that education is at a crossroads in our country. With passage of NCLB,[26] the role of the Federal Government in the education of America's children was transformed more significantly than at any time since passage of the Elementary and Secondary Education Act of 1965. NCLB is still in development, but many of the regulations needed for its implementation have now been published,[27] and a number of issues of particular significance to students with disabilities have emerged.

For all students, including those with disabilities, we stand at a historic turning point. The confluence of NCLB, this year's report of the National Commission on Excellence in Special Education[28] and the imminent reauthorization in 2003 of IDEA creates both grave risks and unprecedented opportunities. The challenge for Congress in reauthorizing IDEA is to develop a statute that meshes IDEA smoothly and seamlessly with NCLB, that carries the positive vision of NCLB into the special education realm, and that respects and preserves those features of the special education system that have allowed so many children with disabilities to learn in integrated classrooms and to take their places in mainstream society.

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[26]The No Child Left Behind Act of 2001, PL 107-110, codified at 20 USC Sec. 6301, implementing regulations at 34 CFR Part 200.

[27]Final Rules Give States Direction, Little Flexibility, by Lynn Olson, Education Week (December 4, 2002); also Public School Choice, Draft Non-regulatory Guidance (U.S. Department of Education) (currently available at http://www.ed.gov/offices/OESE/SASA/schoolchoiceguid.doc).

[28]A New Era: Revitalizing Special Education for Children and Their Families; Final Report of the National Commission on Excellence in Special Education (U.S. Department of Education, Office of Special Education and Rehabilitative Services, July 2002) (currently available at http://www.ed.gov/inits/commissionsboards/whspecialeducation/reports/info.html).

1. NCLB IMPLEMENTATION

With a few specific exceptions, NCLB does not address the issues and concerns unique to students with disabilities. Moreover, it does not always address practical details about how provisions theoretically applicable to all students and all schools are to be applied to students with disabilities. While the NCLB implementing regulations have of course answered many questions about the law, they have also created new questions and concerns. As the NCLB implementation process continues, many of these new questions should be answered as well, and these answers must be widely disseminated throughout the education community.

(a) SCHOOL CHOICE

One area of residual uncertainty is exactly how the new provisions bearing on school choice apply to students with disabilities, particularly in relation to compliance with IDEA requirements and in terms of how the Federal Government will exercise its monitoring and enforcement responsibilities regarding school choice. NCLB makes clear that all students are entitled to the benefits of choice. Where poor school performance triggers the school-choice provisions of the law, all students, including those with disabilities, will have the opportunity to benefit. But the regulations also seem to indicate that the precise range of choices that a local district or local education agency (LEA) offers to students with disabilities receiving services under individualized education plans (IEPs) or under Section 504 plans need not necessarily be identical to the choices offered to other students.[29]

Many factors determine what transfer options must be made available when school choice is invoked. If distance or overcrowding result in the unavailability of a suitable alternative school, then no student, with or without a disability, will have transfer options within the public system. But what about situations where otherwise appropriate schools are available but inaccessible? Are schools exempted from being appropriate alternative placements on this ground?

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[29]Ibid.

Similarly, what, if any, other restrictions can school districts or LEAs impose on the transfer rights of students with disabilities that would not be applicable to their classmates? A complicating factor here relates to funding—not to the adequacy of funding but to how it can be used. The new regulations make clear that special education funding can and should by and large follow students, so that when schools receive new special education students as enrollees their funding will increase commensurately. But the new rules also remind us that special education funding goes not to individual students but to school districts.[30] Clarification of the law's flexibility with respect to funds transfers, including interdistrict or inter-LEA transfers, is needed.

(b) TEACHER TRAINING

NCLB makes clear that teacher competencies must be upgraded and sets forth certification standards for teachers of primary subjects.[31] Because many students with disabilities have continued to receive their education and related services in relatively segregated classes, it appears that a number of special education teachers have, in fact if not in name, become these students' teachers for the primary subjects of the core curriculum.

As testing becomes an increasingly central determinant of student and school success, issues surrounding the training and qualifications of these teachers become all the more pressing. Both from the standpoint of the legal requirements bearing upon special education teachers and from the standpoint of their ability to prepare their students for the increasingly rigorous challenges they will face, the NCLB implementation process needs to include detailed guidance on what training and credentialing requirements will be placed on special education teachers, what resources will be made available to help these already highly skilled and well-trained professionals adapt to the new requirements, and other related questions.

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[30]Ibid.

[31]Compare 20 USC Sec. 1414 (d)(1)(B), 34 CFR Secs. 135–36.

(c) TESTING

At the heart of the NCLB's emphasis on accountability is universal testing. Through testing, the relative performance of every school is to be judged, and their year-to-year changes in performance (revealed primarily by test scores) trigger funding, technical assistance, school choice and other statutory provisions. Once again, though, while in principle students with disabilities are expected to be tested, and their tests results counted along with the outcomes achieved by other students, many key questions remain about how testing is to be done with this population.

For example, because NCLB vests states with considerable authority in choosing tests, the problems of test validation (norming) for use with students with various disabilities are likely to increase with the number of tests in use. Moreover, if testing is to be fair (that is, produce reliable comparisons among all schools using the same tests), then issues of reasonable accommodation such as extra time and use of assistive technology (AT) must be systematically addressed and uniformly resolved. The National Commission on Special Education report recommends that all tests be developed with universal design and that the accommodations that are reasonable be specified for each test. Yet the Commission has not identified or estimated the resources needed for carrying out these assessments, has not recommended that test developers be required to do so as a condition for marketing their instruments and indeed has not addressed whether all tests currently in use can be made fully fair and accessible or can be validated for use with reasonable accommodations.

The Department of Education's August 2000 guidance on the applicability of testing requirements to IDEA remains the most specific authority available on the relationship between IDEA and performance testing.[32] But with the enactment of NCLB, many of its precepts are

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[32]Questions and Answers About Provisions in the Individuals with Disabilities Education Act Amendments of 1997 Related to Students with Disabilities and State and District-wide Assessment (OSEP Policy Memo 00-24, August 24, 2000) (currently available at http://www.ed.gov/offices/OSERS/OSEP/Products/omip.html).

likely to be out of date or superseded by new provisions. Ideally as a baseline for Congress's use in IDEA reauthorization (but if not, then certainly as soon after re-enactment of IDEA as possible), NCD recommends that the Department of Education (ED) update its policy guidance on the relationship between special education and performance testing.

2. THE REPORT OF THE NATIONAL COMMISSION

Although initially scheduled for reauthorization during 2002, IDEA was not reauthorized but received an automatic one-year extension, meaning that it will be a subject of importance and necessary action for the first session of the 108th Congress. As a result of the delay, Congress will have the benefit of the report of the National Commission on Excellence in Special Education in its deliberations.[33] Undoubtedly this report will provide the jumping-off point for much of the discussion on reauthorization, organized around support for and opposition to its specific findings and recommendations, and around questions of how to operationalize its proposals. While bearing in mind the need to review and modernize all programs, NCD recommends that in reauthorizing IDEA Congress remember the accomplishments and achievements attributable to this law. Specifically, in evaluating this report and in assessing special education, as it has existed until now, NCD urges Congress to consider the following points.

(a) THE BASIC PARADOX

One of the basic premises of the Presidential Commission's report is that excessive bureaucracy, paperwork requirements, compliance reporting and other rigidities and technicalities significantly interfere with the educational process. Partly for this reason, the report recommends major revamping of ED's monitoring, technical assistance and other oversight practices.

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[33]Compare Report of the National Commission, Note 28, supra, with Individuals with Disabilities Education Act Reauthorization: Where Do We Really Stand? (NCD, July 2002) (currently available at http://www.ncd.gov/newsroom/publications/synthesis_07-05-02.html).

At the same time, a number of studies, including NCD's 2000 Back to School on Civil Rights report,[34] have catalogued a pattern of inadequate monitoring and underenforcement over many years, almost to the point of virtual nonenforcement, of IDEA by ED, spanning administrations of both parties. Perhaps not surprisingly, Assistant Secretary of Education for Special Education and Rehabilitative Services Pasternack has indicated that no state is in full compliance with IDEA.[35]

How could it be then that we have an excess of regulation, control and paperwork on the one hand, and a shortage of monitoring and enforcement on the other? Put another way, is it possible that both these conditions exist simultaneously? The report offers one possible explanation for the paradox by noting that checklists of federally required stipulations have grown to more than 814 items, leading the Commission to conclude that because of an emphasis on "process compliance" rather than outcomes and results, a school could in theory comply with all these requirements while not necessarily providing students with a quality education. The Commission does not estimate how many of the 814 compliance items have real educational value, let alone how much better off students with disabilities might be if the law had been enforced in reality as much as it was on paper.

In its characterization of the sea change that special education must undergo, the report juxtaposes a law that emphasizes procedural requirements and evidence of compliance with an environment that places primary emphasis on accountability for results and outcomes. But as suggested by the paradox just noted, compliance and accountability should not be regarded as opposites or as mutually exclusive. To create an effective program, they must exist together. Accordingly, NCD recommends that Congress provide authority and resources for effectively monitoring all aspects of the revised IDEA over the coming years.

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[34]Back to School on Civil Rights, Note 1, supra.

[35]Testimony before the United States Senate, March 21, 2002 (quoted in National Commission Report, Note 28, supra).

(b) MONITORING

In recognizing the need for more targeted and focused monitoring, albeit on a smaller number of criteria and on the basis of broader and more general guidelines, the President's Commission on Excellence in Special Education report reflects an awareness that national standards continue to play an important role. Indeed, if compliance with uniform national standards were not still an important element of the federal approach, the regulations implementing NCLB would hardly be as lengthy and detailed as they are. Given its focus on the excesses of compliance monitoring and on the evils of a "culture of compliance," the report makes no specific effort to identify the strengths of the existing special education model. Perhaps all critical studies necessarily suffer from a preoccupation with what is wrong, and perhaps a focus on the negative is a necessary precondition for all major reforms of any system, but we must be mindful that special education has accomplished tremendous results for America, and we must therefore be careful to preserve what works while eliminating and replacing what does not.

In asserting that no demonstrable link exists between IDEA compliance monitoring and student performance, the Commission has created a proposition that should not exist and has failed to recognize some of the historic goals of special education. For example, the Commission appears to believe that process compliance was an issue early in the development of special education because of the need to identify whether or not and how much service was being provided; however, the Commission believes this information is now no longer needed. Yet, without at least some information on the process, how can anyone determine whether such IDEA-mandated goals as parental involvement, education of students in the least restrictive environment, or appropriate utilization of AT are being met?

It is seductively simple to say that student performance or comparative state performance data will tell Congress and the public all they need to know about the adequacy of services or the effectiveness of the new law. However, student and school and state performance data, including test scores, graduation rates and other end results, will tell little about nonquantifiable but key

variables of the educational system such as those just noted, and in those cases in which performance fails to improve as expected, test results unaccompanied by appropriate process information will give little insight into either the causes or the solutions for the problem. On the contrary, appropriate compliance monitoring remains the only way for ensuring the educational and related service inputs necessary to bring about the desired outcome goals and results.

(c) IEPs AND PARENTAL RIGHTS

The report sharply condemns the existing IEP process, quoting one administrator who characterizes the current IEP as a "litigation document."[36] The Commission proposes to replace the current IEP with a document that will be judged by student outcomes. While Congress must still flesh out the details of this proposal, some of its implications warrant discussion and concern.

First, although simple and attractive on its face, this proposal means that IEPs cannot be challenged or evaluated until their expiration, since the results by which they are to be judged will presumably not be known any sooner. The Commission also rejects the use of short-term "benchmarks." The nature of parental involvement will be dramatically changed under this proposed new structure. Additionally, if an initially appropriate IEP proves inadequate or requires modification because of changed circumstances, what opportunity for making such changes will exist, and what formal input opportunities will parents possess during the duration (typically one year under current law) of the IEP?

The report recommends a high degree of parental involvement and choice in the educational decisionmaking process, but it is far from clear what leverage parents would have when they and educational officials and experts have differing views. In the absence of any mention of the subject in the report, we can only assume that the backloaded IEP evaluation process

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[36]National Commission Report, Note 28, supra.

recommended by the Commission would eliminate any legal ground for parental objection to the terms of their child's plan. As such, it is difficult to know what the new parameters for parental empowerment in the IEP process would be.

Clearly, as the report's discussion of the need for dispute reconciliation, binding arbitration and other conflict-resolution mechanisms makes clear; the Commission is not unmindful that such disagreements will arise. However, the Commission's references to the defensive purposes and legalistic nature of the IEP process suggest it does not look favorably on existing due process rights accruing to parents and families.

It is unknown whether the Commission sought or received testimony from any parents who had been able to achieve higher quality results or educationally instrumental services for their children through use of the due process provisions embodied in the current law. If the Commission did hear from such parents or from successful graduates, they would know how often a high level of assertiveness was required to obtain the necessary services. While the culture of high educational expectations the Commission hopes to produce should over time result in IEPs that reflect students' highest potentials, current practice is described by many parents as reflecting low expectations on the part of many school systems. Without due process to bolster the role of parents while the transformation in the culture of expectations takes place, what will happen in the meantime? Having identified the need to raise expectations as a central problem, the Commission cannot trust solely to the good offices of educators to bring that about.

Accordingly, NCD recommends that in its review of the Presidential Commission's report Congress seek testimony from parents and students who have been obliged to utilize due process in order to overcome low educational expectations, and who have benefitted from the services and outcomes their determination brought about.

Additionally noticeable, and frankly ominous in this regard, the Commission calls for mediators and arbitrators to be drawn from outside of education or disability advocacy. While such

personnel should be trained in conflict resolution and negotiation, the notion that they should be ignorant of education or of the issues faced by individuals with disabilities is little short of frightening. However skilled they may be in smoothing feelings and cooling tempers, is it not of equal or greater concern that they have some in-depth knowledge about the subjects and the destinies they may be helping to adjudicate?

Anecdotal evidence reaching NCD over the years suggests that the admitted problems with the IEP process may have as much to do with the need of school districts to cloak economic decisions in educational justifications as with the desire of unrealistic parents or avaricious lawyers to rush into court. In any event, the point is the need for balance. As long as schools are obliged to filter their placement, services and other special education decisions through the prism of costs, as they will always be required to do, the right of parents to contest those decisions in impartial settings will be crucial to the vision of accountability and performance that the Commission upholds.

(d) ELIGIBILITY DETERMINATION AND ASSESSMENT

Rejecting the 13 categories of disability currently used to determine eligibility for special education services under IDEA, the report opts instead for a three-category classification system; 90 percent of currently covered students would be in the Category 3 group, which includes a variety of disabilities now assessed by psychometric, behavioral and emotional tests. With respect to several of the more controversial disability categories comprising Category 3, namely, mental retardation and emotional disturbance, the report devotes welcome attention to the over-representation of students from culturally diverse backgrounds in these groups. Without postulating a statistical correlation, the report plainly suggests that teacher referrals are the source of a high proportion of the referrals in these and other "high-incidence" disability categories.

While this finding suggests the commission's belief that reliance on teacher referrals is connected to the rise in absolute numbers as well as to the over-representation of culturally

diverse children within special education, the report also criticizes non-classroom-based assessment instruments and argues for assessments based on classroom observation and on documentation of the behavioral and academic results of classroom interventions. Thus, while implicitly disparaging teacher evaluations, the report appears to increase the likelihood that teacher evaluations will become the basis for diagnosis and categorization.

NCD shares the Commission's serious concerns, as documented by the National Research Council, about the over-representation of culturally diverse children, especially African American males, in certain culturally influenced or inherently subjective diagnostic categories. We agree that use of culturally inappropriate IQ or other tests may contribute to this problem. But without significant investments in teacher training, reliance on the dynamics of the classroom may well serve to exacerbate rather than to solve the over-representation problem, especially in schools or communities where, due to high class size or other conditions, the opportunities for individualized intervention are limited. Accordingly, NCD recommends that Congress consider the scope and availability of resources that will be necessary to effectively impact the high-incidence diagnosis problems cited by the Commission. In considering this issue Congress must also bear in mind that correction of the culturally diverse over-representation problem, and indeed reduction in the overall rate of increase in the number of students found eligible for special education services, will also depend in large part on the ability of teachers and schools to provide adequate educational and related services. It may well be that some students are being misdiagnosed because of poor educational performance, which could be remedied by remedial education services but that, in the absence of such services, results in the students' misclassification as special education eligible.

(e) FEDERAL FUNDING

While recommending a number of significant changes in the federal funding formula for Part B special education services, the Presidential Commission does not support a concerted effort to bring federal participation up to the so-called full-funding level of 40 percent of special

education costs. NCD has strongly recommended such increases, bearing in mind that this level of funding was part of the original intention of those who created the program (see, for example, http://www.ncd.gov/newsroom/publications/synthesis_07-05-02.html, for information about NCD's recommendations).

Faced with this reality, we commend a number of the Commission's financial proposals, especially its recommendations for targeting extra federal support toward defraying the costs associated with extremely high-needs, high-cost students and those allowing for the pooling and carrying-over of unspent funds to create safety nets, and for related purposes. Such measures, however, will not solve the basic problem.

Special education and vocational rehabilitation are unique among major programs serving people with disabilities, in that they are entitlement programs without any entitlement. This means that anyone who meets the eligibility requirements of the programs has an absolute right to services, but the funding of these programs is discretionary with Congress. Vocational rehabilitation has been empowered to deal with this dilemma by allowing states to declare an "order of selection,"[37] under which they can temporarily cut off services to those who, though meeting statutory eligibility standards, are determined to have less severe needs. Special education, on the other hand, does not have this option. As long as this legal situation exists, educational and budgetary decisions are likely to remain impenetrably intertwined in ways that complicate and obscure each alike. We certainly do not advocate applying "order of selection" or measures to reduce eligibility for special education, since education is a fundamental right for all children. We do believe though that accountability cannot be fully achieved as long as educators have to hide budgetary decisions behind educational rationales. Accordingly, without attenuating the responsibility of the public school system to provide special education services to all students found eligible for them, NCD recommends that Congress look for means by which the relative roles of educational and budgetary considerations in school system decisionmaking about

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[37]34 CFR Sec. 361.36.

individual children can be more clearly separated and differentiated than has hitherto been the case.

(f) CHARTER SCHOOLS

The national commission endorses maximum flexibility in school choice for students with disabilities, recommending amendment of IDEA to allow special education funds to move with students and recommending amendment of other laws to further this flexibility. The report also urges states to ensure an equitable flow of various types of funding to charter schools. Missing, though, is any reciprocal requirement that when children with disabilities exercise choice to attend charter schools, such schools will be willing to accept or required to accommodate them. Without such reciprocal requirements, a significant element of choice may all too often represent an empty promise.

Ironically, the Commission's recommendation that charter or other choice schools be held to the same standards of accountability as regular public schools may work to increase barriers to their accepting students with disabilities. Small or experimental schools, especially anxious to achieve high test scores to establish their franchise, may be unwilling or afraid to risk the burdens, the diversion from their particular focus or the perceived risk of accommodating students with severe disabilities, particularly those falling into the sensory and physical-neurological disability groups identified by the Commission. Only by including strong antidiscrimination requirements in IDEA can this risk be adequately averted. Accordingly, NCD recommends that Congress incorporate into IDEA strong antidiscrimination provisions aimed at ensuring that charter and other choice schools receiving funds, whether directly or indirectly, under NCLB or other federal programs be reciprocally required to provide the identical services and accessibility to students with disabilities that public schools would be required to provide.

3. OTHER ISSUES

A number of other concerns, raised in NCD's last status report but not addressed by the national commission, remain critical to the reauthorization of IDEA. As a backdrop for consideration of the issues that follow and all the issues surrounding IDEA reauthorization, NCD urges Congress to review our IDEA reauthorization synthesis paper[38] and the recent report of our Youth Advisory Council.[39]

(a) ASSISTIVE TECHNOLOGY

AT represents one of the most important modalities for enabling students with a broad range of disabilities to participate and learn in the mainstream classroom. From the powered mobility device to the augmentative communication device to the assistive listening system or the synthetic speech output computer, this technology has revolutionized the lives of students with disabilities much as the technology it tracks has transformed the classroom experience for students without disabilities. For this reason, NCD, through many studies and reports, has continued to advocate for procedures that will ensure the fullest possible utilization of appropriate AT on behalf of students with disabilities through the IEP process.

To the degree that AT is not an outcome in the sense that term is used by the national commission, enactment of the Commission's recommendations may leave us in a situation where the scope and effectiveness of AT implementation and student assessment for AT cannot readily be known. Some may argue that the quality of AT assessments and inputs can be inferred from academic results, but more direct information and criteria are needed. The danger is that with AT devices and services needed by students with low-incidence disabilities, the system of accountability proposed by the national commission may actually create disincentives to the

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[38]Individuals with Disabilities Education Act Reauthorization, Note 33, supra.

[39]National Council on Disability Feature: Youth with Disability Speak Out (NCD, 2002) (Currently available at http://www.ncd.gov/newsroom/news/f02-383.html).

maximum use of AT. This is so because even if, as seems obvious, the failure to provide and use AT will result in lower test scores for some students with disabilities, the number of such students may be too small to make a material statistical difference in the overall performance of some larger schools and some school districts. If aggregate scores are not affected by AT policy, whatever the devastating impact of its denial on individual students with disabilities, the following question must be asked: What incentives or what mandates will the law contain to ensure its provision and use? Ironically, too, the smaller schools and districts, with presumably the least resources to provide AT, will face the greatest statistical need to do so, because for them the consequences of poor performance by even a few students may prove statistically and competitively more significant.

Accordingly, NCD recommends that Congress take steps to ensure that accountability extends to the use of and the assessment of students for AT.

The IDEA reauthorization of 1997 required that consideration be given to AT in the identification of student needs and in formulating IEPs, but that law included no specifics as to the form such consideration should take and no documentation requirements regarding the extent or nature of such consideration. While no data have been found that shed material light on how this provision of the law was handled by school districts around the country, it is clear that the requirements of the 1997 reauthorization insufficiently ensure thorough assessment of AT needs and possibilities in the IEP process.

(b) ACCESS TO MAINSTREAM SCHOOL TECHNOLOGY, INSTRUCTIONAL MATERIALS AND MEDIA

When we mention AT, as discussed above, we ordinarily think of devices, peripherals or software specifically designed for use by people with disabilities in performing various functions and tasks. Leaving aside the economic, design and attitudinal issues surrounding their use, these devices, such as assistive listening systems or computers with speech output, pose no conceptual

difficulties. What they do and why is usually fairly self-evident, especially once people observe them in operation. But with the technology needed to make mainstream school equipment and instructional resources accessible, the conceptual as well as administrative issues are a good deal more complex.

As electronic media become an ever more central part of the curriculum, the importance of making such media and school computers accessible grows increasingly critical. From an administrative standpoint, a key challenge in making mainstream school technology accessible is integrating general and special education technology funding. In its report, the PCESE speaks of a need for better melding of resources, but offers little guidance on where this need is greatest or how such cross-statutory flexibility can be achieved. Suffice it to say, as indicated in last year's NCD status report, while education officials recognize the obligation to make school buildings physically accessible as a need that must be met out of mainstream construction funds, they do not always demonstrate comparable recognition of the need to make school computers, tech labs and other communications technology accessible as well. Too often, they contend that such expenses are the responsibility of special education and should not, or even cannot, be met out of general-purpose funds.

Like adding a ramp to a building after it has been constructed, the costs of retrofitting communications technology and infrastructure are typically far higher than the costs of incorporating such capabilities into the basic procurement and design strategy. Remitting these expenses to special education would mean that accessibility need not be implemented until requested by a specific student, parent or staff member, by which time (as with installing the ramp or widening the bathroom doors) it would be far more expensive and potentially undoable. Unless the reauthorized IDEA includes mechanisms for ensuring that accessibility will be treated as a core school obligation, and unless the law includes compliance monitoring that places accessibility among the accountability measures of record, differential access to educational technology and resources will undermine our aspirations and high expectations as surely and as relentlessly as exclusion from the school building would. No one would countenance exclusion

of students from school buildings because of disability. We cannot permit their exclusion from the curriculum or the learning process once inside the building. Accordingly, NCD recommends that IDEA make clear that the requirements that apply to physical access to school facilities are also applicable to program participation, including access to E&IT resources and educational media included in the mainstream curriculum.

Textbooks represent one area in which the technical and administrative issues surrounding accessibility have been widely discussed. We would not dream of giving a textbook to one student in a class while denying it to another, yet this is exactly what happens when inaccessible textbooks available only in print are given to blind students or when videos without captions are presented to deaf students. It would be one thing if the technology for making most textbooks and related educational media accessible did not exist or were too expensive or difficult to use, but such is not the case.

In 2002, ED commenced an effort with various stakeholders to develop voluntary textbook accessibility standards.[40] In seeking to create a national consensus, ED was responding to the varying and sometimes inconsistent textbook accessibility laws enacted in approximately half the states. While we hope the department's efforts will result in a high level of agreement and in the articulation of workable standards, we question the use of a voluntary approach. Since inconsistent state laws will not be overridden or negated by voluntary federal standards, we fail to see how the promulgation of such standards will solve the problems facing textbook publishers in their efforts to comply with state law.

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[40]The Instructional Materials Accessibility Act of 2002 (HR 4582, S. 2246) would have required textbook publishers to submit textbooks in standard electronic file formats, if voluntary standards setting by ED did not succeed. This bill was not passed, and the Education Department opted instead for a totally voluntary National File Format standardization effort. Even if successful, such voluntary guidelines will not override state laws or solve the problem posed to publishers by varying state requirements.

Assuming that viable standards can be developed, NCD recommends that ED make these standards mandatory. We believe that federal law, including Title II of ADA and Sections 504 and 508 of the Rehabilitation Act, as well as provisions of IDEA, supports such action. In any event, the IDEA reauthorization should include provisions making clear that accessibility of textbooks and other educational media and materials is required, no less than accessible building entrances are. Accordingly, NCD recommends that ED take steps to implement regulations making mandatory such textbook accessibility standards as its current voluntary consensus-building effort yields, and if its efforts result in no such consensus, that the department nevertheless adopt suitable regulations by no later than the end of 2003, based on the findings made and the best practices discovered during the next year.

Health Care

The United States has among the finest and most advanced health care in the world, but the systems for delivering that care to many of our citizens are under severe strain and, in some sectors, in crisis. The problems are no mystery, even if their solutions are elusive. These problems include shortages of adequate primary care (particularly in inner-city and rural areas); overuse of hospital emergency rooms in the face of a decline in the number of such facilities; rising insurance premiums in the private sector that preclude individuals from purchasing or employers from providing coverage; declining incomes and growing dissatisfaction among doctors; escalating scarcity of physicians willing to treat Medicaid or Medicare beneficiaries; opting out by managed care organizations from coverage in various areas and of various subgroups of the population; narrowing definitions of what is covered and increasing co-payments and deductibles (resulting in larger out-of-pocket costs to the fully insured); growing numbers of Americans without any health insurance; crushing prescription drug costs; and, most recently, sharp cutbacks in state Medicaid programs, among others.

No one is satisfied with the current system, yet no one can bring forward anything approaching consensus recommendations for reform. Recognizing that in matters of accessibility, availability, affordability and adequacy of health care, persons with disabilities are the proverbial canary in the mineshaft, NCD has followed and contributed to the evolution of health-care policy for more than a decade.[41] As with every year, 2002 has witnessed the emergence of new perspectives and new emphases in the public discussion of the issue. This chapter addresses both the core issues of concern over the years and the particular issues likely to predominate in congressional and executive branch reform efforts during 2003.

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[41]e.g., Major chapters in each of NCD's annual progress reports. See also such recent examples as Position Paper on Patients' Bill of Rights (March 30, 2001) (currently available at http://www.ncd.gov/newsroom/publications/patientsbillofrights.html); also, Society's Great Challenge: The Affordability of Long-Term Care (testimony of Marca Bristo, submitted to the Senate Committee on Finance, April 18, 2001) (currently available at http://www.ncd.gov/newsroom/testimony/bristo_4-18-01.html).

1. GENERAL CONSIDERATIONS

In last year's status report, NCD offered detailed recommendations for any major health-care reform legislation, such as a patients' bill of rights. Like many, we had hopes that Congress and the President would be able to formulate a new vision for health, as they had for education, and we remain hopeful this may prove possible in the 108th Congress.

To reiterate briefly these basic principles, NCD believes that to be inclusive of Americans with disabilities, any reform legislation must bar all plans and carriers from refusing to insure otherwise eligible individuals solely on the basis of disability; include provision for the availability of specialized care and practitioners that people with disabilities may need; provide for continuity of care for persons with chronic health problems or specialized care needs who cannot find suitable substitutes among the new roster of providers when provider networks change; call for standing referral or other flexible referral mechanisms for the predictable, specialized needs of people with disabilities; mandate that legally required information be effectively communicated to persons with disabilities who cannot access print or spoken information; ensure that if coverage for clinical trials is included as a part of any insurance coverage, it not be limited to pharmaceuticals but be available to test the safety and efficacy of AT and community-based interventions as well; and include mental health parity.

Last year's report also included recommendations for several pilot demonstration and research projects designed to shed light and potentially allay cost-fears regarding broadening of the standards used to determine medical necessity and the implications of more functionally based methods and standards for evaluating various proposed inputs and interventions. Pending broad-based reform, we believe these studies should be carried out. Specifically, they would involve controlled experiments testing and demonstrating provision of appropriate AT to persons with disabilities, carried out under conditions where the actual effects on costs, benefits and outcomes of such provision could be carefully measured, and under circumstances where the financial exposure of participating insurers or self-insured plans would be strictly limited.

2. MEDICARE

(a) PRESCRIPTION DRUGS

Because of its urgency for so many Americans, the issue of prescription drug coverage for senior citizens is high on the agenda of both political parties in the 108th Congress. Originally designed for an era in which hospital and other acute care typically represented the largest out-of-pocket risk for senior citizens, Medicare does not generally pay for prescription drugs except as an incident of hospital or other institutional care. As the role of pharmaceuticals in long-term health management has grown, and as drug costs have skyrocketed, their omission from coverage has become increasingly problematic.

Whatever the decision on this and other structural issues, we do believe that certain precepts must be followed for the program to meet the needs of those for whom it is intended.

Perhaps the key issue for people with disabilities is the need for recognition that they are included among Medicare recipients. Many over the age of 65 have disabilities, but Medicare also includes persons under 65 who are eligible for Social Security Disability Insurance (SSDI) as well as persons participating in several return-to-work programs. In light of the unfortunate precedent set in several states that have adopted senior citizens prescription drug programs that omit or exclude Medicare recipients under 65, an adequately inclusive federal response cannot be taken for granted.

Accordingly, NCD recommends that the congressional statement of findings underlying any prescription drug legislation include detailed demographic information on the number of persons with disabilities included in the age, beneficiary or other categories of persons covered by the new law, and the number likely to be included as time goes on.

NCD believes an inclusive approach to prescription drug coverage should contain a drug formulary that includes drugs needed by persons with low-incidence conditions; provisions requiring that complete information about the program and any options be fully accessible to beneficiaries with disabilities (including usage instructions, warning labels and package inserts); provisions mandating effective communication (including sign language interpreters) for all informed consent forms or face-to-face discussions; requirements that those whose current Medicare Part B premiums are subsidized by Medicaid will also receive this support for new premiums associated with the prescription program; assurances that for persons dually eligible for Medicare and Medicaid the new benefit will not be used by states as grounds for withholding any available pharmaceutical benefit under the state Medicaid or related programs; and guarantees that if certain pharmacies are designated to handle drug dispensation, they are held to standards of accessibility or if not accessible will provide auxiliary aids and services to allow persons with disabilities to fully avail themselves of covered services.

To whatever extent any new prescription drug benefit may be means tested, Congress must also remember that Medicare recipients with disabilities under the age of 65 are likely to have lower average income than the Medicare-recipient population as a whole. Since we expect the Administration to propose market-based reforms dealing not only with prescription drugs but also with other Medicare issues, Congress should keep these economic disparities carefully in mind in its consideration of all proposed Medicare reforms. Accordingly, NCD recommends that if economic eligibility standards are used to determine eligibility for any benefits, Congress take notice of all available data concerning the income of Medicare recipients with disabilities under the age of 65, whose average incomes are likely to be lower than those of the Medicare-recipient population as a whole.

An additional concern relates to the ways that market-based strategies may be used. If the Administration and Congress decide to use managed care or other forms of private insurance as the primary vehicle for providing prescription drug services, situations may arise in which people with disabilities choose not to join the insurance plan for good reasons unrelated to prescription

drug availability, losing potential access to such medicines as a result. For example, what if a managed care provider, while now offering prescription drugs, does not pay for specialist's services that an individual needs?

The new program must ensure that this scenario does not happen. Therefore, NCD recommends that any prescription drug plan provide assurances that otherwise eligible people with disabilities who decline for specified reasons to join the plan will still be entitled to obtain the drug benefits available under the new program.

(b) APPEALS

Because of its uniqueness and complexity, the Medicare appeals process may be more misunderstood and under-utilized than that of many other programs. Because a major thrust to modernize the appeals process has begun this year under the authority of the Medicare, Medicaid and State Children's Health Insurance Program (SCHIP) Benefits Improvement and Protection Act of 2000,[42] attention to the effect on beneficiaries with disabilities of the proposed changes is timely and important.

In Medicare the insurer does not generally pay up front for services, nor is there a prior authorization process. This means that with respect to durable medical equipment (DME) or other goods and services that beneficiaries with disabilities may need, the beneficiary must buy the item first, then seek reimbursement. Only after reimbursement is denied is there anything to appeal, but this system means that only those who can pay the cost to begin with ever reach the point of being able to appeal a wrongful denial.

Regulations published late this year by the Centers for Medicare and Medicaid Services (CMS) implementing the legislation purport to speed the appeals process by placing time limits on the

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[42]The Medicare, Medicaid and SCHIP Benefits Improvement and Protection Act, 107th Cong., HR 5661, added in PL 106-554.

process at several levels of appeal, and by giving appeal rights that did not previously exist.[43] A problem that remains unaddressed by these new regulations reveals another unique feature of Medicare. Many of the Medicare appeals involving goods and services that would be of particular concern to people with disabilities (such as AT, safety-related home modifications, accessible home monitoring or home care equipment, or DME) would be governed by what are known as "national coverage decisions." As a result, one would have to go several levels up the appeals chain before a hearing officer or appeals tribunal would have legal authority to overturn a denial of a claim for many of these goods and services, even if the denial were plainly wrong on medical grounds.

In 1999, CMS's predecessor agency undertook a systematic review of national coverage decisions, but only one national coverage decision—barring provision of augmentative communication devices to people with speech disabilities—has been repealed.[44] Many others remain in effect, though likely based, as the aug-com rule was, on little or no medical justification, often lacking even economic justification. Recognizing the technicalities that largely insulate these national coverage decisions from judicial review or medical assessment, in last year's report, NCD urged CMS to undertake a comprehensive review of these provisions. To our knowledge, this review has not yet been made. Accordingly, NCD recommends that CMS proceed with its prior undertaking and establish a timely and transparent process for identifying and reviewing the efficacy of all existing national coverage decisions, with a view to modifying or repealing those that cannot be justified in light of current medical thinking or law.

If CMS is not in a position to undertake a comprehensive review of its national coverage decisions, Congress should take further actions to make the Medicare appeals process more accessible and responsive to beneficiary concerns. Among the most pressing reforms, Congress

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[43]See proposed implementing regulations published by the Centers for Medicare & Medicaid Services (CMS), CMS Notice of Proposed Rulemaking at 67 Fed. Reg. 54534 (August 22, 2002) and 67 Fed. Reg. 69311 (November 15, 2002).

[44]CIM 60-9.

should consider means by which Medicare beneficiaries who cannot afford to front the costs of needed technology or services without some assurance of their reimbursibility can obtain advance determination of coverage, including the right to appeal on an expedited basis where warranted if the initial determination is negative.

In addition, just as all new regulations adopted by federal agencies are subject to economic impact analysis, old regulations that withhold cost-effective preventive care should also be subject to cost-benefit review. Congress should begin by experimenting with this approach on Medicare's national coverage decisions.

3. MEDICAID

Even as it is widely recognized to be in need of overhaul, Medicaid finds itself deeply in crisis. And the implications of this crisis bear most heavily on low-income recipients with disabilities. Put simply, the problem is this: As states face budgetary shortfalls unknown since the Great Depression, they look to cut large items in their budgets. As one of the largest and fastest-growing budget items in many states, Medicaid is an attractive source of savings. The problem is that because of the way the Medicaid law is structured, only optional, and not mandatory or waiver, services can be easily, massively or quickly cut. Many of the services of greatest importance to people with disabilities are provided under these rubrics. Thus, while services such as nursing homes and hospital care are mandatory, home9 and community-based waiver services and even efforts to implement the *Olmstead vs. L.C.* decision[45] are not.

A terrible meltdown in the quality of life, and even in the safety and health of many people with disabilities, is realistically and imminently foreseeable. Faced with this calamitous prospect, NCD recommends that Congress urgently and immediately hold hearings to examine the impact

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[45] *Olmstead v. L.C.*, 527 US 581 (1999) (currently available at http://caselaw.lp.findlaw.com/cgi-bin/getcase.pl?court=us&navby=case&vol=000&invol=98-536).

of state Medicaid cuts on the lives of people with disabilities, including hearings that assess the number of people likely to be forced into institutions as a result and the costs of such institutionalization to the program, and that Congress consider and adopt measures to prevent this needless tragedy and counterproductive fiscal result.

4. PAIN RELIEF PROMOTION VERSUS ASSISTED SUICIDE AND ABUSE

In the past two annual status reports, NCD has discussed issues raised by proposed legislation on pain relief (such as the Pain Relief Promotion Act of 2000) and related concerns of assisted suicide (such as those raised by Oregon's Death with Dignity Act). While DOJ has forcefully articulated national policy opposing assisted suicide, a national framework guaranteeing compassionate pain relief to those who suffer has yet to be developed. As medical care prolongs life, we run the risk of perpetrating a cruel hoax on many people, including older persons and many persons with disabilities, if we do not devote significant attention to quality-of-life issues, including pain relief.

Discussion of possible federal pain management legislation has focused on such issues as whether the use of controlled substances should ever be permitted, what procedural safeguards should be put in place to guard against concealment of assisted suicide (or even homicide) under the guise of pain management, and issues of state versus federal jurisdiction. While of overriding concern, these matters do not address all of the issues of importance to individuals with health conditions and disabilities involving chronic or acute pain. For this population, likely to be disproportionately represented among persons intended to be protected by any new law, other issues include access to AT, personal assistants' and other home- and community-based services necessary to ensure a minimally tolerable quality of life; access to information about the variety of modalities and services available that may contribute to function, self-esteem and community

involvement; and freedom from abuse masked as care on the part of professional caregivers or even family members.[46]

Unless we pay sustained and balanced attention to the quality of life, we do not honor life for those in pain and our protestations of valuing life become hollow and cruel. Attention to the factors that induce some people to consider ending their lives may do far more to prevent its needless forfeiture than even the most stringent control of doctors and medications.

For all these reasons, NCD renews its recommendation for the creation of a broadly diverse national commission to look into the issue of pain management and life preservation, with a view to comprehensively assessing not only the medical, legal and ethical issues, but also the support services and other complex needs and issues involved, and for the purpose of developing a national policy that will ensure that life with dignity, not death with dignity, commands our resources and attention.

5. FDA APPROVAL OF MEDICAL EQUIPMENT

Legislation adopted in 2002 fundamentally reforms the medical device approval process of the Food and Drug Administration (FDA).[47] Backlogs and delays in the review of medical devices—a prerequisite to their widespread use, to their availability in various contexts and to their reimbursibility under much insurance—have become a matter of increasing concern. To remedy the problem, an approach similar to that previously developed to address the same problem in the pharmaceuticals sector has been adopted. Medical device manufacturers will now pay fees to the FDA to defray the costs of expediting device review.

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[46]Position Paper: Assisted Suicide: A Disability Perspective (NCD, 1997), currently available at http://www.ncd.gov/newsroom/publications/suicide.html.

[47]Note 5, supra.

While speeding up the process of bringing medical equipment to market is highly desirable, it is unclear how the new approach will affect review timeframes and availability of medical devices that fall within the AT category. Many of the companies that produce DME and other AT devices may be smaller or newer companies, and concern exists about how the resources made available by contributions from the industry will be allocated and whether smaller AT companies will be expected or able to contribute to the new fund. If they cannot, will their devices be eligible for expedited review?

NCD hopes the new law will be implemented with sensitivity to these considerations. We recommend that all medical device review procedures be evaluated in terms of their impact on DME and other AT devices used by persons with disabilities. Beyond this, we recommend that CMS and the FDA undertake a review of the legal issues surrounding the assessment and eligibility for insurance coverage of that broad range of AT that may not fall within the jurisdiction of the FDA as medical appliances or devices but that is nevertheless evaluated under medical-device standards by health insurers or other third-party payors.

6. CONSUMER-DIRECTED HEALTH SERVICES

A number of recent measures reflect a growing awareness of the need for consumers to take a greater role in selecting the modalities and providers through whom they will receive care and in helping to examine overall policy for public and private health-care programs. NCD commends these efforts and is attempting to contribute to them by issuance of a request for proposals (RFP) for research into the existence of models for enhancing such input.[48]

Pending the results of this study, we wish to commend CMS for establishing open-door forums for public discussion of Medicaid issues;[49] for implementing two new Independence Plus

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[48]NCD Presolicitation Announcement of Consumer-directed Health Care RFP (NCD Bull. October 2002) (currently available at http://www.ncd.gov/newsroom/bulletins/b1002.html).

[49]CMS Open-Door Forum Initiative (http://www.cms.gov/opendoor/).

Medicaid waiver programs (discussed further in the next chapter), and for releasing significant comparative information on the quality of care afforded by the nation's estimated 17,000 nursing homes.[50]

Amid this succession of positive moves, NCD must also urge the administration to reconsider funding for a number of consumer-direction projects deleted from its fiscal year (FY) 2003 budget proposal.[51] We must also note that consumer information of the sort now available about nursing homes, while contributing to informed choice and enhancing the ability of prospective residents and their families to ask the right questions, cannot by itself either improve the overall quality of such care or provide the alternatives to institutionalization that most people with disabilities and an increasing number of older Americans believe are so greatly needed. In addition, for those persons with limited private means, without friends or family to advocate for them, or who may be dependent upon Medicaid or other public funding sources, practical choices may be very limited despite the valuable consumer information about residential care facilities now being made available.

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[50]See 9 of 10 Nursing Homes Lack Adequate Staff, Study Finds, by Robert Pear (New York Times, February 18, 2002); DHHS Nursing Home Compare Database (http://www.medicare.gov/Nhcompare/home.asp).

[51]NCD Letter to President George Bush (February 22, 2002) (currently available at http://www.ncd.gov/newsroom/correspondence/bush_02-22-02.html). Compare NCD Letter to Federal Consumer Information Center (April 23, 2002) (currently available at http://www.ncd.gov/newsroom/correspondence/levy_04-23-02.html).

7. MENTAL HEALTH

(a) SYSTEMIC REFORM

In its 2002 report The Well Being of Our Nation,[52] NCD provided an intergenerational analysis of the serious shortcomings of the existing public mental health system for persons of all ages. Chapter 6 of the 2002 report contains a discussion of service-provision models that have worked, including notably those featuring consumer-control elements, but the report concerns itself primarily with analyzing the root causes of the crisis facing mental health services in our country today.

We need not reiterate the findings of this study here except to note the unique feature of effective mental health services that it documents: namely, that the problems associated with a psychiatric diagnosis are not limited to the need for treatment. Indeed, in many ways the problems only begin once treatment has succeeded in stabilizing function, for it is then that issues of housing, transportation, support services and continuity of care, employment and sadly pervasive discrimination and fear begin to assert themselves.

NCD commends President Bush and the Administration for establishing the New Freedom Commission on Mental Health, and the Commission's findings and recommendations should spark much needed action. The Commission's task will not be an easy one, since to have the intended impact it must make recommendations that, in addition to being innovative, point the way to a level of interagency and interdepartmental coordination equal to that still being sought in connection with implementation of the *Olmstead* mandate. Indeed, adequate community mental health services will surely be one key element of the *Olmstead* implementation plan, if

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[52]The Well-being of Our Nation: An Inter-generational Vision of Effective Mental Health Services and Supports (NCD, 2002) (available at http://www.ncd.gov/newsroom/publications/mentalhealth.html).

deinstitutionalization is to be achieved for persons with current or past mental illness and persons with physical disabilities alike.

NCD has communicated with the New Freedom Commission[53] and pledges its continued efforts and resources to assist the Commission in its vital work. Pending the Commission's findings, a number of measures can be taken.

(b) PARITY IN HEALTH INSURANCE

In last year's report, NCD called for an end to sharp distinctions between physical and mental illness in the availability and amounts of health insurance offered to groups and individuals. We pointed out many of the benefits that would accrue from progress toward parity and questioned the basis for categorical distinctions between physical and mental illness in light of modern medical findings showing the complex interconnection of the mind and body in all illness and in light of treatment protocols that through the use of drugs implicitly regard mental illness as organic. Finally NCD recommended several carefully controlled research studies designed to ascertain what the actual costs of parity would be to the insurance industry, and through that industry to subscribers and purchasers of health coverage.

While such research cannot allay the noneconomic fears that surely contribute to the particular difficulties faced by people with mental health backgrounds in attempting to obtain insurance, such studies could go a long way to eliminating economic fears among insurance providers and purchasers. GAO reported on some of these and related issues (see http://www.gao.gov/new.items/d02239.pdf). In this report, entitled Access to Health Insurance for Applicants with Mental Disorders, GAO determined that a significant number of health insurance carriers would likely decline applicants 52 percent of the time. GAO acknowledged

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[53]NCD Letter to the President's New Freedom Mental Health Commission (NCD, September 17, 2002) (currently available at http://www.ncd.gov/newsroom/correspondence/newfreedom_09-17-02.html).

that health insurance is an important factor influencing whether individuals with mental disorders have access to treatments that can be effective in diminishing the symptoms of disorders and improving individuals' quality of life. Absent treatment, according to the U.S. Surgeon General, many individuals with mental disorders may suffer increased incidents of lost productivity, unsuccessful relationships and significant distress and dysfunction. Untreated mental disorders among adults can also have a significant and continuing effect on children in their care.

As noted in above, even an increase in insurance coverage for mental health will not solve the problems disclosed by NCD's new report. To the degree that those problems involve institutions and service systems outside the scope of any health insurance, they will continue to require broad public health approaches and solutions that utilize insurance, not as a solution, but as a partner in the overall effort.

(c) AMERICA'S LAW ENFORCEMENT AND MENTAL HEALTH PROJECT

During the past year considerable media attention has been directed to the question of whether or not persons with mental illness or retardation should be subject to the death penalty for murder. In one of the first cases in history to decide a disability-related issue on constitutional grounds, the Supreme Court ruled that execution of an individual with severe retardation was an unconstitutional violation of the Eighth Amendment's ban on cruel and excessive punishments.[54]

For many people, this debate may be the only time they have ever thought about the intersection between mental illness, retardation and the justice system. Yet, recognition that the criminal justice system is becoming the leading control mechanism for persons with cognitive, perceptual, emotional and mental disabilities is widespread. Such recognition helped lead to the enactment in

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[54]*Atkins v. Virginia,* US (No. 00-8452, June 20, 2002).

2000 of legislation authorizing the attorney general to make grants for the establishment of pretrial diversion projects for nonviolent, minor offenders with mental disabilities.[55]

Through close supervision, case management and coordinated provision of necessary services, these judicial alternatives are intended to give minor offenders with mental retardation, or co-occurring mental retardation and substance abuse, the opportunity to avoid conviction and incarceration by participating in programs of treatment and training. While NCD welcomes any program that diverts persons with cognitive disabilities or mental illness out of the criminal justice system and into services and treatments, we also recognize the risk of coercion and of harmful interventions inherent in the mental health court system, or indeed in any diversion program. Accordingly, reiterating a major item contained in last year's report, which has become if anything even more timely and pressing, NCD recommends that DOJ issue an overview and update of the implementation of the America's Law Enforcement program to date and consider means for involving people with mental illness and psychiatric treatment histories in the development and oversight of the program. We reiterate this recommendation now.

At a time when rising prison populations are coming under scrutiny in states facing budget crises, measures that combine the protection of society with the more appropriate treatment of offenders are increasingly worthy of exploration and development. For people with disabilities, whose imprisonment is likely to accomplish little by way of meaningful punishment, rehabilitation or deterrence, the need for alternatives is especially great. Provided that coercive participation, compulsory treatment and other counterproductive measures can be avoided, such programs as the mental health courts should hold out potential of reducing the costs of incarceration, protecting society from crime and contributing to the return to a fuller participation in society of a substantial number of persons. Such an opportunity should not be missed, but until data are made available on what the program has done and learned so far, planning for additional measures remains tentative. We recommend that DOJ seize the opportunity offered here to help

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[55]PL 106-515, Sec. 2201, codified at 42 USC Sec. 3796ii. See NCD's juvenile justice Notice of Solicitation of 12-7-01 at Fed Biz Opps.

develop the most effective possible interplay between the criminal justice and mental health systems, bearing in mind that even a public mental health system that operates far short of the ideal is still in most cases superior to prison, brutalization and recidivism for persons who can readily be spared a life of futility or crime.

Long-Term Services and Supports

In its 2002 study entitled Federal Spending on the Elderly and Children, the CBO determined that for FY 2000 the Federal Government spent $615 billion on persons over the age of 65 and $148 billion on children.[56] These figures highlight the belief of some that governmental resources are disproportionately directed toward transfer payments and services for older persons at the expense of the young. What makes these findings important, though, is not the numbers themselves but rather the dangerous potential for intergenerational conflict that they portend.

Debate over Social Security reform likewise focuses on the intergenerational aspects of the system. As the ratio of current workers to retirees falls, the prospects for maintaining benefit levels out of payroll taxes grow more daunting. Advocates of reform contend that the necessary payroll tax increases are far greater than either the economy or the younger workers will be able or willing to bear.

Whether in insurance programs or transfer payments, whether on or off budget, the costs of caring for both the growing population of senior citizens (many of whom will be people with disabilities) and persons with disabilities under the age of 65 will continue to grow rapidly. Demographics alone, including the projected doubling between 1980 and 2030 of the number of Americans over 65, make this inevitable, even without regard to changes in per capita costs. Moreover, drastic recent declines in middle class wealth resulting from the implosion in the value of stocks is likely to further exacerbate the economic pressures faced by older Americans and may increase the dependence of baby boomers on public-sector programs. Faced with growing pressure on resources to defray long-term services needs, society has an obligation, never more pressing, to use the available resources wisely.

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[56]Federal Spending on the Elderly and Children (Congressional Budget Office 2002).

Questions of cost-shifting aside, the overall expense to society of serving and supporting people with disabilities and aging Americans (a high proportion of whom will also have disabilities or functional limitations approaching the legal threshold for disability) in their own homes and communities will be far less than the cost of housing and caring for them in nursing homes or other institutions. Part of the needed funds must come from diversion and redirection of the estimated 73 percent of federal long-term care funds currently targeted to institutional care.[57] However, even if we can accomplish the enormous attitudinal, legal and economic changes necessary for this diversion of funds, such reallocation of existing resources will not by itself suffice to meet the need.

Compelling as the long-term fiscal arguments are, the primary argument for aging in place and living in place is not rooted in economics. Few people would choose institutional care over their own homes and neighborhoods, if allowed to make that choice with dignity, autonomy and comfort. A February 2002 HHS study revealed that as many as 90 percent of the nation's nursing homes may face staff shortages that compromise adequate resident care.[58] For all these reasons, the variety of initiatives summarized under the *Olmstead* rubric can be said to carry with them the destiny of a generation.

Creation of a paradigm to meet these new needs and fulfillment of the *Olmstead* promise on behalf of institutionalized or at-risk Americans with disabilities (seniors and younger persons alike) presents structural, resource allocation, public-private partnership, coordination and federalism issues of unprecedented and sometimes baffling complexity. NCD has repeatedly praised the commitment of the Bush Administration through the NFI to the values of ADA, as

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[57]Delivering on the Promise: Preliminary Report of Federal Agencies' Actions to Eliminate Barriers and Promote Community Integration (Department of Health and Human Services, December 21, 2001) (currently available at http://www.hhs.gov/newfreedom/presidentrpt.html).

[58]Note 50, supra.

embodied in the Supreme Court's 1999 *Olmstead vs. L.C.* decision.[59] As indicated by President Bush's 2001 executive order and the subsequent coordinated planning, the Administration recognizes that new levels of interagency cooperation and high-level oversight will be necessary for the success of *Olmstead* in ensuring that Americans with disabilities can live (as they have already long been legally entitled to learn and to work) in the most integrated settings possible.

But in 2002, new concerns have arisen over the sustainability of progress, as the *Olmstead* initiative confronts major new challenges while still endeavoring to surmount the old ones.

1. FEDERAL COORDINATION

As the initial participation of nine major federal agencies in the comprehensive planning process under the President's June 2001 community-based living executive order attests, few policy initiatives involve so many agencies and programs as *Olmstead*. In order to marshal the community resources necessary for the success of *Olmstead* (that is, to enable people to leave institutions and to prevent at-risk citizens from entering them), the resources, procedures and priorities of over a dozen traditionally separate and self-referencing service systems, funding streams and statutory jurisdictions must be coordinated. At a minimum these include, at the federal level, Medicaid (both regular and waiver programs), transportation, housing, AT, attendant services, food and nutrition programs, Older Americans Act, Social Security Administration (SSA), community development block grants, independent living and veterans benefits, along with private insurance and pensions and state and local programs with their rules and discretionary interpretations of federal provisions. Even the tax system is implicated in the success of *Olmstead*, insofar as the costs of many categories of home care and assisted living services do not qualify for deductibility, whereas equivalent costs, if encompassed in the fees charged by nursing homes, can lower the middle class family's or individual's tax obligation

[59]Note 45, supra.

The nature of the coordination required to make *Olmstead* and the NFI work may well exceed the administrative and planning resources currently available for the purpose. Recent experience in other spheres of policy has demonstrated the enormous difficulty of, and the entrenched institutional and jurisdictional barriers to, achieving seamless, coordinated interagency action, based on shared goals, methods, information resources, timeframes and standards of accountability, among divergent federal agencies, each with its own budget, institutional culture and chain of command. While no one would suggest drawing the agencies primarily responsible for *Olmstead* implementation into a single chain of command, the key problem remains that no one agency is capable of making or carrying out plans in ways and according to timeframes that fully anticipate and reflect the related plans and activities of all the other key participants.

Until or unless coordinating structures such as the Interagency Committee on Community Living can be constituted with the resources and authority to accomplish or compel coordinated planning, the best planning efforts of any one agency may be all too easily negated by the varying priorities or differing time horizons of another, or even of another entity within the same department or under the same management.

These coordination problems also emerge in the budgeting process. *Olmstead* implementation is not a budget line or cost center in its own right. Thus, when the budgets for the various programs, statutory responsibilities and functions making up the work of each agency are determined, impact on *Olmstead* is hardly the key variable determining whether or how much programs will be cut. While one agency may develop its budget recommendations and requests to the OMB and Congress with *Olmstead* in mind, others may not.

As a result, NCD recommends that the OMB and the CBO begin developing cross-agency program scoring methods and unified budgeting models that will link the relevant activities and budget requests of various agencies so as to allow the impact of budget proposals on multi-agency policy initiatives such as *Olmstead* to be tracked and reported and to allow effective budgeting for multi-agency initiatives.

In connection with coordination, NCD commends the administration for two major NFI-related initiatives during 2002: establishment within HHS of the Office of Disability and creation of two new Independence Plus waiver programs within Medicaid. The Office of Disability should contribute considerably to coordination within HHS and the agencies it supervises and may develop linkages with similar coordinating offices in other departments that will add further coherence to the federal effort. The new waiver programs reflect important early steps toward infusing consumer-directed community-based services by giving states more flexibility to direct funds in accordance with beneficiary choices.[60]

But as encouraging and innovative as these measures are, they may in the end serve as much to highlight the seemingly intractable problems of coordination as they do to resolve them. For in the absence of interconnected and timely actions by other departments, the effects of what any one agency does in the *Olmstead* context may be considerably diminished. It does little good, for example, to give an individual the option to use Medicaid waiver funds to provide home-based services rather than going to a nursing home (to allow for the money to follow the person) if no accessible housing is available in the community that can meet the individual's needs, or if no accessible or affordable transportation is available between the accessible housing and other locations in the community where the individual needs or wishes to go. Without transportation, the isolation of one's own home can all too easily become as crushing as that of an institution.

2. ADDITIONAL FEDERAL INITIATIVES

(a) PUBLIC-PRIVATE PARTNERSHIPS

Any full-fledged effort to make the promise of *Olmstead* and Title II of ADA a reality depends upon both private-sector and public resources. So far as the resources of individuals and families are concerned, we have already noted that, even for people of sufficiently modest means to qualify for Medicaid (particularly where spend-down is used), tax laws may play a role in

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[60]http://www.cms.hhs.gov/independenceplus

influencing key personal and life choices. Along similar lines, for people of all income levels, another key variable is availability and affordability of long-term care insurance that does not force policyholders into nursing homes.

In the current discussion of health-care reform, access to insurance is a major issue. Although the tax code has already been used to enhance the ability of self-employed persons to pay for health insurance,[61] what has been missing from the discussion are suggestions for ways that tax policy and other forms of positive leverage could likewise be used to increase the supply and quality of private disability insurance that would help defray the costs of staying in one's own home. Various models of coverage, including partnerships between insurance and Medicaid, already exist, but other models that specifically emphasize the meeting of in-home and community-based care costs, rather than devoting their resources primarily to nursing homes, are needed.

So long as coverage tips the scales in favor of nursing homes by providing vastly smaller and patently inadequate benefits for home- and community-based services and by defining covered services in ways that further the bias in favor of institutional care, no viable private-sector participation in solving this problem is likely. NCD recommends that Congress should hold hearings and invite recommendations on coverage packages, including seller and purchaser incentives, that would help to meet the existing and foreseeable needs for greatly expanded private-sector participation in the financing of home- and community-based services and care. If such new models are to effectively combine public and private resources, they must also encompass structural changes in the Medicaid and Social Security programs—especially Supplemental Security Income (SSI). For example, if the proceeds of private in-home care insurance coverage were treated as income and hence used to reduce payments under SSI (or other means-tested programs), or if they were subjected to spend-down requirements under Medicaid, then the value of such insurance might be limited to those people whose means are already sufficient not to need the public programs at all. NCD does not presume to know the

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[61]With tax returns for 2002, small business owners are entitled to deduct 100 percent of their health insurance premiums, in many cases.

answer to such questions or how the necessary programs should be designed and incentivized. The point of mentioning the issue here is to suggest an example of new types of coordination that must be confronted at the outset in any sort of meaningful planning.

(b) STATE INITIATIVES

The coordination issues encountered in implementing *Olmstead* in the federal sector are mirrored at the state level and, indeed, depend in large measure on what the states do. Everything must begin with an *Olmstead* plan, but a major advocacy organization reports that as of the end of November 2002, fewer than half the states had *Olmstead* implementation plans in effect.[62]

Although some states have done very well (embracing *Olmstead* out of commitment and/or pragmatism), anecdotal evidence suggests that other states have followed a path of reluctance and resistance, perhaps going through the motions of planning but in the end putting few if any significant mechanisms into place. Whatever the explanation for the variation in states' responses, the fact that more than half the states have not moved effectively to implement *Olmstead*, more than three years after it was decided, raises troubling questions regarding both state capacity and federal commitment.

The prospect in many states of huge cuts in Medicaid to help close budget deficits adds further obstacles to *Olmstead* implementation and NFI success and further urgency to getting started. Waiver programs, proportionally perhaps even more than regular Medicaid, are likely to be affected by these cuts. While painful Medicaid cuts are inevitable, HHS and CMS should find means (within the scope of their regulatory and oversight authority) to identify the kinds of cuts least destructive to burgeoning *Olmstead* initiatives and should do everything possible to encourage states not to make these kinds of cuts. CMS should also provide additional technical

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[62]Report by Mark Johnson on meeting between ADAPT and officials of the Department of Health and Human Services (distributed November 30, 2002, on Justice For All listserv and archived through their site, http://www.jfanow.org).

assistance to states on what Title II of ADA requires and share exemplary state plans that have thus far been developed and put into effect.

More broadly, NCD recommends that the Administration conduct and publish a comprehensive audit of all state-based *Olmstead* implementation activities, designed to describe what has worked, to name names of states that have been successful or that have at least tried as well as of those that have not, and to make certain that citizens and voters are as fully informed as possible about the values at stake in the responsiveness or unresponsiveness of their state officials and leaders. Anecdotal information about state responses to *Olmstead* suggests that neither partisan affiliation nor position of the state government on the ideological spectrum is a predictor of states' responses. Only when we know what has worked, why some states have embraced *Olmstead* and others not and why some have met with noticeably more success than others can we hope to engender the galvanized response so desperately needed if the transition and deinstitutionalization that *Olmstead* betokens can reach critical mass across our nation.

Youth

Issues of special concern to youth discussed in this report are of two kinds. First, the subjects that bear upon youth more specifically and immediately than on the population as a whole are addressed. Second, the issues and programs about which youth have had (or should have) input are discussed.

1. TRANSITION SERVICES

(a) UNIQUE TIMING

The expected reauthorization of both IDEA and the Rehabilitation Act in 2003 creates an unprecedented opportunity for coordinated planning and implementation in many areas, but perhaps none so crucial as that of school-to-work transition services. Never before have IDEA and the Rehabilitation Act been reauthorized in the same year. Accordingly, NCD recommends that with respect to transition or other major areas of overlap between the two statutes, Congress develop means to ensure coordination in the drafting and review of provisions and to ensure consistency between the languages included in each reauthorization. NCD also recommends that Congress direct appropriate agencies to effectively coordinate their resources, staff and program efforts to achieve the transition goals of the laws.

For example, despite detailed though not identical language in both statutes,[63] considerable uncertainty and disagreement persist regarding allocation of costs for goods and services needed to implement effective transitional services in school-to-work or secondary-to-postsecondary education settings. In such areas of ambiguity, we believe that only inclusion of identical language in both laws will finally clarify disputes that continue to result in the consumption of time and the dissipation of resources through unproductive cost-shifting exercises, in which no

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[63]Compare 29 USC Sec. 705 (37) with 20 USC Sec. 1400 (30).

one disputes that in the end one program or the other is obligated to pay. Moreover, the new laws should address situations where disputes over eligibility for various covered services contribute to the cost-shifting problem.

(b) THE CHANGING LANDSCAPE

Although not officially involved in the transition process under any law, a number of other major entities have become progressively more concerned with transition. Obviously transition bears upon the Medicaid program in connection with the role Medicaid or other insurance should play as a source of funding for AT required in the educational setting (and that relationship will no doubt be further refined in the IDEA reauthorization).

Transition also concerns the SSA. In conjunction with other agencies, and in recognition that all too many youth with disabilities are consigned to the benefit rolls because of inadequate systems for transitioning into higher education or self-supporting adult activities, the SSA sponsored a nationwide series of Youth Preparing for Tomorrow conferences in late 2001.[64] These yielded invaluable new insight into the scope of transition issues as understood by youth, family members and others with knowledge and experience of the process.

From the findings of these conferences and from other outreach it has become clear that more than just the services and resources of the special education and vocational rehabilitation (VR) systems are implicated in successfully negotiating the passage from school to adult life. Adequacy of health services, reasonable predictability of income supports and access to AT, transportation and mainstream educational and labor market resources are all implicated in individual outcomes.

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[64]See NCD 2001-2001 Progress Report, Chap. 6, Section 2.

Recognition of the contemporary nature of transition issues also comes from a survey of youth with disabilities conducted by the National Youth Leadership Network.[65] Youth were asked to rank the importance of various issues—health services, knowledge about reasonable accommodations and reliable transportation were among the top seven. Interestingly, none of the top choices were strictly academic, but instead dealt with these and other services, with self-assertion and self-advocacy techniques and skills and with similar competencies not traditionally included in classroom education.

Most of these ramifications of the transition problem are outside the scope of this chapter. Also not discussed here are the issues involved in the newly emerging transitional setting of the movement between career paths for adult workers with disabilities in a society where multiple job and career changes are becoming the norm. Suffice it to say, while the reauthorized vocational rehabilitation (VR) and IDEA laws must deal clearly with the responsibilities for transition that they share, no one should imagine that the issues implicated in transition are bounded by the jurisdiction of these two programs.

(c) ACCOUNTABILITY FOR RESULTS

Although not yet formally a part of our nation's workforce development programs and laws, NCD assumes that "accountability for results" will be incorporated into the Workforce Investment Act of 1988 (WIA) reauthorization[66] as it will be incorporated into IDEA. Few areas cry out for accountability more than transition, yet suitable outcome measures for this package of services have to date escaped policymakers' ability to define, measure and report.

Outcome criteria must relate to the postsecondary school placement and outcomes that students achieve. The Presidential National Commission on Excellence in Special Education contemplates

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[65]Ibid.

[66]The term "accountability for results" does not appear in NCLB, although references to accountability abound throughout the statute.

the collection of such data but offers no guidance on how it would be evaluated or factored into availability of technical assistance or of alternatives for students not being well served. More fundamentally, unlike other activities where accountability rests with individual schools or school districts, evaluation of transition outcomes is inevitably complicated by the involvement of two separate service systems, with all the cost-shifting and territoriality that such relationships all too often denote.

Only by making educators and rehabilitation providers equally and jointly responsible for the success or failure of transition can accountability be achieved. New mechanisms must reward, assist and, where necessary, sanction both service systems in tandem, leaving to them the determination of how their shared responsibility and mutual self-interest can be parlayed into effective and cooperative programs.

It is a measure of the difficulty surrounding so many interagency coordination efforts that although VR and special education are both overseen by the same cabinet department (Department of Education), anecdotal information about their relationship and interactions at state and local level suggests that while many examples of success can be cited, in all too many other instances the relationship suggests not so much a close organizational affiliation as residence on different planets. This must change.

NCD believes that experience with multi-agency cooperation under *Olmstead*, and our nation's broader recognition that its most serious problems transcend agency boundaries or statutory jurisdictional lines, have combined to create a fruitful environment for progress along these lines. But the legal and administrative infrastructure must be designed to enhance the new awareness and commitment. Among the structural features that would contribute to success are provisions facilitating transfer of ownership of AT between service systems or providing for joint ownership; provisions clarifying the role of school funds in out-of-school components of transitional plans and of VR funds in in-school components; provisions allowing parents to bring disputes between transitional service providers before appropriate officials for quick and binding

arbitration; and provisions clearly delineating the outcome measures that will be used to determine the effectiveness of transition services and the timeframes within which they will be assessed. Finally, the new laws must provide means for regularly gathering and incorporating student input into the design of transition programs at the local and state levels. This matter is addressed further in the following section. In order to experiment with such mechanisms, NCD recommends that discretionary grants be made on a trial basis to education–rehabilitation agency partnerships for transitional services, with success or failure and the availability of further funds to be contingent on the development and achievement of unified transition goals and without any opportunity for accountability being differentiated between them.

2. NATIONAL YOUTH LEADERSHIP NETWORK AND LOCAL YOUTH COUNCILS

(a) NATIONAL YOUTH LEADERSHIP NETWORK

The National Youth Leadership Network (NYLN) is a five-agency–supported effort aimed at involving youth in formulating and evaluating the programs and services that affect their lives and through its leadership training component is aimed at developing the next generation of leadership in the disability community. Along with four line agencies—the Department of Education, Department of Labor, HHS and the SSA—NCD is proud to be involved in this project. As noted above, the NYLN has given valuable feedback on transition issues, as well as contributing in other key areas.

Among the concerns and recommendations listed as "Areas of Quality Improvement" in its 2002 annual report, the NYLN identified two areas in connection with the leadership conference component of its project. One was the need for small-group discussion time in which participants gave input on national issues, with national leaders as mentors and facilitators. Another was the need for conference-supplied personal assistants who are knowledgeable about how to provide youth-directed support. As we did in last year's report, NCD recommends that the

Administration clarify its support for the NYLN and explore its fullest empowerment and most effective utilization.

We renew this recommendation here, urging the Administration to find ways, beyond intergovernmental review processes, for involving youth with disabilities in the development and evaluation of policy and program initiatives, especially the important initiatives coming out of the NFI. As part of a broader program of public involvement, which the newly enacted E-Government Act[67] may facilitate, involvement of youth in the programs shaping their and our futures is entirely appropriate and can be done without demeaning the authority and responsibility of cognizant agencies and officials. The E-Government Act will be discussed further in Chapter 11.

(b) YOUTH COUNCILS

To inform the work of the local workforce development boards created under WIA,[68] that statute also created local youth councils.[69] As suggested last year, NCD recommends that the Department of Labor's Office of Disability Employment Policy (ODEP) inquire systematically into the operation, integration and impact of the youth advisory councils, with a view to making suggestions for their continuance and improvement in the WIA reauthorization this year.

The environment for labor market entrants today is as grim as any time in the past 10 years. This environment places a greater premium on job selection, technological knowledge, self-presentation skills, transportation, flexibility, resilience and other individual and environmental

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[67]The E-Government Act of 2002, PL 107-347, codified at 44 USC Sec. 3601.

[68]The Workforce Investment Act of 1998, PL 105-220, Sec. 117.

[69]Ibid. at Sec. 117 (h).

variables than any labor market before it. Under these circumstances, the experiences and insights of youth (both those who have successfully and those who have not yet succeeded in crossing this perilous divide) are indispensable to making and validating local workforce development policy. We urge the Administration to make certain this resource is being used to its fullest potential.

With WIA also due for reauthorization, the question of whether or not and in what form these local youth councils should be continued takes on new importance. As part of the reauthorization process, NCD recommends that Congress seek testimony from young workers to determine how their input into the operation of programs affecting them can be most usefully provided, and how such programs can be most effectively designed and implemented.

Employment

For Americans with disabilities, no less than for all other citizens, the opportunity to earn a living and be self-supporting is a universally held goal. Yet in perhaps no area of public policy has the expectations gap so stubbornly resisted our efforts to achieve equality. Whatever set of statistics one chooses from among the varying estimates of disabled Americans' employment rates, the rate and level of employment for this population remain far too low.

1. THE TICKET TO WORK AND SELF-SUFFICIENCY

This year marked a turning point in the effort to bring Americans with disabilities fully into the employment mainstream, for 2002 witnessed implementation of the Ticket to Work and Self-Sufficiency program under the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA).[70] By the end of 2002, "tickets" (which allow their holders to obtain VR, training and placement services from various providers) were scheduled to be issued to SSDI and SSI recipients in 33 states, with the remaining 17 scheduled to come on-line in 2003.

While it is too early to assess any impact from the new law, preliminary reports indicate that our hopes must be tempered by concern and watchfulness. Provisions of the TWWIIA statute itself and factors outside the scope of the program combine to raise concerns.

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[70]PL 106-170, The Ticket to Work and Work Incentives Improvement Act of 1999.

(a) REDUCING WORK DISINCENTIVES

For SSI and SSDI recipients, TWWIIA was intended to reduce disincentives to working in at least two major ways. The statute creates both new opportunities for obtaining vocational services and new methods for retaining health insurance after leaving the benefit rolls. First, the ability to use the ticket to obtain vocational services from various employment networks was intended to give recipients greater choice and more likelihood for achieving their employment goals. But for recipients who lose cash benefits as a result of entering into paid employment, the law provides new and expanded opportunities for re-establishing eligibility for program cash benefits if employment is subsequently lost. Unfortunately, the limited anecdotal evidence available so far suggests that the complexity of the new provisions, in themselves and as they relate to the underlying SSA, may leave many of its intended beneficiaries more confused than ever about their status and options.

Two of the most important new anti-incentive provisions contained in TWWIIA will illustrate this problem. Ordinarily, benefit recipients are subject to periodic recertification through what are called continuing disability reviews (CDRs). One of the key TWWIIA work incentive provisions suspends the conduct of medically based CDRs for beneficiaries while they are using their tickets to obtain services or participate in programs. CDRs based on work are not suspended, however. In other words, while using the ticket an individual will not be deemed to have ceased having a disability because of medical improvement. But benefits can of course be reduced or terminated on account of the income derived from employment.

If a ticket user has lost eligibility for cash benefits because of earnings from employment, but then loses the job, the law also provides for expedited reinstatement (EXR), which allows cash benefits to be quickly restored for up to six months, while the fuller determination of eligibility for their long-term reinstatement is being made. This is important because under the regular Social Security Act, reinstatement of cash benefits takes much longer.

As this comparison between TWWIIA and the Social Security Act indicates, while the ticket's EXR provisions create new procedures easing the transition to employment and leaving open the way back if employment fails, they also help to create a new legal structure that parallels and interacts with a well-established prior body of law under the Social Security Act, but often in confusing or even contradictory ways. For instance, the provision of the Social Security Act for mitigating work disincentives that EXR parallels is the extended period of eligibility (EPE). How the EPE and the new EXR overlap and when EPE still applies and when EXR does have become questions of concern to experts, and potentially sources of doubt and fear to recipients.

Returning to the CDR for an example of uncertainty that arises solely from within TWWIIA, the new law, as just noted, suspends most medical CDRs for recipients while their tickets are "in use," but the meaning of "in use" turns out to be less than self-evident. Whether or not a person's activities amount to adequately using the ticket is decided at regular intervals by the TWWIIA program manager on a case-by-case basis.

With the help of its statutorily created TWWIIA Advisory Panel, the SSA is actively engaged in completing the regulatory provisions to implement the ticket program. Despite its thoroughness and care in attempting to resolve uncertainties and fill in the gaps, the TWWIIA implementation process is not a viable forum for correcting underlying omissions or incongruities in the law itself, or for resolving inconsistencies, potential conflicts or gaps between TWWIIA and other closely related major statutes.

As these and other examples make clear, although the new law has reduced some major disincentives to working, it may not have simplified the processes of decisionmaking or of actually utilizing the new work incentives. Significant advisory, educational and technical assistance resources are available from various sources, including state Medicaid infrastructure grants; the protection and advocacy (P&A) systems under the auspices of the Protection & Advocacy for Beneficiaries of Social Security (PABSS) program and through the benefits planning, assistance and outreach (BPA&O) program, but the complexity of the law strongly

suggests that explaining it and empowering individuals to use it represent a daunting long-range task. Accordingly, NCD recommends that the SSA consult with its TWWIIA advisory panel, with the PABSS and BPA&O units of state P&A programs, with TWWIIA employment networks and with Social Security beneficiaries who have attempted to use the new law to determine whether its complexity has proven to be a barrier to effective utilization, and if so to identify technical assistance tools, regulatory or even statutory changes that might make the program more accessible and user-friendly. As part of the TWWIIA Advisory Panel's research agenda, measures should be taken to ensure that this underlying concern is fully studied and discussed.

(b) HEALTH INSURANCE

The second major way TWWIIA sought to reduce disincentives to work was by providing mechanisms so that people could keep their Medicare or Medicaid health insurance for substantially longer periods than was formerly possible after going to work. All too often, the risk of the loss of these priceless benefits, rather than the risk of an end to cash benefits, inhibits beneficiaries from leaving program rolls.

In addressing this need for insurance continuity, TWWIIA did not arise in a vacuum. It had to build on existing provisions governing Medicare (which is the primary form of coverage ordinarily available to SSDI recipients) and Medicaid (which is what SSI recipients utilize). As budgetary deficits at federal and state levels threaten the funding for these programs, the critical implications of such cuts once again demonstrate how changes in one service system can dramatically impact the cost and efficacy of others. For example, if states decide to save Medicaid funds by eliminating or foregoing buy-in programs under TWWIIA, then the availability of one of the principal work incentives in the new law will be seriously compromised.

Faced with this risk, NCD recommends that the Administration and Congress speedily address the question of whether or not Medicaid cuts are jeopardizing the success of work incentive provisions in TWWIIA aimed at preserving health insurance for Medicaid recipients who return to work, and if so to devise means for restoring the ability of the states to participate fully. The Administration must first identify the extent to which existing or planned buy-in programs have been canceled or curtailed in the states, then determine and provide such financial resources or nonmonetary structural incentives as would be necessary to bring about the fullest possible utilization of this mechanism. Since Medicaid buy-in under TWWIIA is by definition only available to persons earning income and paying taxes, few measures could be more cost-effective.

(c) TWWIIA AND THE VR SYSTEM

In a related vein, the 2003-scheduled reauthorization of the Rehabilitation Act (discussed in section 3 of this chapter) provides an opportunity for the review of other crucial connections between TWWIIA and the broader vocational rehabilitation (VR) system. One area of concern in this regard relates to the status of ticket holders who attempt to access state VR agency services in states operating under order of selection procedures, meaning states that have had to delay or deny VR services to otherwise eligible persons because of resource limitations. Since many services that ticket holders need in order to work, such as technology, may be obtainable only through state VR agencies, serious questions exist regarding how such needs can be met in the potentially significant number of states operating under order of selection. NCD recommends that the Rehabilitation Services Administration (RSA) and the SSA develop guidelines for dealing with requests for VR services from active ticket holders, where the state VR agencies in question are operating under order of selection procedures that restrict the provision of the needed services.

2. THE OFFICE OF DISABILITY EMPLOYMENT POLICY

NCD has applauded the Administration and Congress for creating and supporting ODEP within the Department of Labor (DOL). DOL is the primary venue for workforce development programs for the general public, but it shares that role, with ED, in connection with Americans with disabilities. ODEP's important role of coordination and leadership can be made only more difficult by this diffusion of financial and administrative oversight and responsibility, yet that role could not be more important if coherence and accountability for results are to be achieved in developing employment opportunities and attaining successful employment outcomes for Americans with disabilities.

With completion of the work of the Presidential Task Force on Employment of Adults with Disabilities during 2002, the time is especially appropriate for ODEP to take the lead in evaluating the extent to which the Task Force was able to carry out the mandate of, and achieve the results anticipated for, it in the 1998 executive order bringing it into existence. Depending upon the findings of this assessment, additional research and policy measures may be indicated. In the meantime, other urgent priorities already exist.

Based on recommendations and findings of previous NCD reports and from other sources, we recommend that ODEP address the following issues through public inquiries or targeted research:

- The extent to which the one-stop centers established and funded under the WIA have effectively served job seekers with disabilities, including the accessibility of their physical premises, their resource materials, and their communications and information technology;

- The degree to which DOL entities incorporate and enforce nondiscrimination requirements in the variety of job training, employment development and other programs they support, license or operate;
- The extent to which operators and administrators of DOL-funded programs are aware of their nondiscrimination and reasonable accommodation responsibilities; and
- (acting through the New Freedom Initiative) The extent to which similar activities supported by other government agencies, including the work of the VR, vocational education and other specialized systems operated under ED jurisdiction, fare with respect to the above-referenced criteria.

NCD also urges ODEP to work with the Office of Personnel Management (OPM) and the OMB on internal workforce development practices in the Federal Government, with a view to determining the efficacy of recent and proposed measures to improve access for persons with disabilities. Key among these was the OPM requirement that all posted federal job vacancy announcements include notice of availability of reasonable accommodations to federal employees with disabilities. Congress and the Administration need to know the level of compliance with this requirement, and more broadly how, at what cost, with what budgetary impact, within what timeframes and with what degree of employee or applicant involvement these reasonable accommodations are actually being provided.

As noted above, ODEP will face a new challenge in 2003 with the reauthorization of the WIA, which includes the Federal Rehabilitation Act. How vocational rehabilitation of persons with disabilities should be integrated into our nation's overall workforce development system remains a matter of great concern and much controversy.

3. REHABILITATION ACT REAUTHORIZATION

When the WIA was adopted, the reauthorization of the federal-state vocational rehabilitation services program for persons with disabilities (the Rehabilitation Act) was included as its Title 4. At that time, considerable controversy surrounded the degree to which the existing VR system should be retained or merged into the new workforce development system that the WIA was creating. In the end, Congress sought to achieve the best of both approaches by retaining the state VR system but creating opportunities and requirements for cooperation between VR and the newly created local work investment boards, one-stop job centers and other WIA entities.

NCD believes that any successful approach must ensure that the mainstream labor force development and job placement system of our country has the capacity and the motivation to serve individuals with disabilities on the same basis as everyone else. We also recognize that without specialized resources and technical expertise, both to assist and to supplement the work of the mainstream system, the goals of equal opportunity and employment outcomes cannot readily be achieved. Provisions that require and encourage the fullest possible mix of timely and appropriate services, that emphasize consumer choice and input, that ensure the incorporation of the concerns of people with disabilities into overall policy decisions and that reward cooperation will be essential to bringing these results about.

Pending submission of specific legislative language by the Administration or by congressional oversight committees, NCD will refrain from addressing detailed issues. We hope to provide our experience and expertise to Congress through appropriate testimony as work on the legislation proceeds. For the moment, it is enough to note that accountability for the VR program will require resources and will require that the results of program activities be measured according to results, which reflect the real opportunities afforded to individuals with disabilities. Hence, the criteria by which the service system is to be judged should reflect the criteria noted above but should also include considerations of job quality, potential for upward mobility and tenure, and availability of technological supports.

In this connection, an opportunity for the assertion of leadership by ODEP, working in conjunction with the RSA, may lie in the need to offer state VR agencies guidance in identifying training resources and employment categories to be pursued and encouraged on behalf of their service recipients. NCD recommends that as part of the reauthorization Congress seek testimony on the extent to which state VR agencies obtain and utilize labor market information and labor-demand forecasts, and how such data are used in fashioning their services, outreach and programs.

An additional area of concern relates to the involvement of persons with disabilities in the work of the local workforce investment boards around the country. Informal accounts from around the country suggest that in fulfilling their legal obligations for consumer participation, these crucial local planning entities have not always reached out to or welcomed consumers with disabilities or representatives of the VR system.

4. TAX INCENTIVES

A GAO study completed in late 2002[71] concludes that the three major Internal Revenue Code provisions aimed at enhancing the employment of persons with disabilities cannot be demonstrated to have had significant effect. This doesn't mean tax policy can't play a profound role, however. In the case of the three employer incentives studied by GAO—the disabled access credit, the work opportunity credit and the architectural and transportation barriers deduction—it is not clear what the impact of the incentives has been.[72] Some possible factors described by GAO include limitations and anomalies in the language of these provisions, undue rigidity in their interpretation and application by the IRS, and inadequate effort in publicizing and explaining them to the accounting, business and taxpaying communities.

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[71]Business Tax Incentives: Incentives to Employ Workers With Disabilities Receive Limited Use and Have an Uncertain Impact (US General Accounting Office, GAO 03-39, December 2002) (currently available through http://www.gao.gov).

[72]Internal Revenue Code, Secs. 44, 51 and 190, codified at 26 USC Secs. 44, 51 and 190.

Tax policy will likely play a pivotal role in economic recovery and growth proposals the Administration will make early in the 108th Congress. The Administration's belief in tax policy as an engine of job creation should be kept in mind when programs to further employment of people with disabilities are being discussed. With attention to the nuances of its proposals, the Administration can ensure that measures in which it places its faith will reach and benefit everyone.

Pending details of the economic stimulus tax proposals, discussion of specific recommendations would be premature. Historically, there has been no consideration of inclusion of persons with disabilities in the development of such proposals. NCD offers its resources and expertise to the Administration and Congress in developing proposals that will reach the greatest number of intended beneficiaries, and we are confident that with attention to the details of stimulus proposals, the goals of economic recovery and of the New Freedom Initiative can be simultaneously and reciprocally advanced.

Welfare Reform

Since 1996 our nation's welfare system, including most notably the TANF program, successor to Aid to Families with Dependent Children, has been governed by the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996.[73] PRWORA was due for reauthorization in 2002 but was deferred until 2003. Moreover, since the 107th Congress authorized extension of the TANF program only through March 31, 2003, the new Congress may have to move quickly on the matter.

Much of the debate over this reauthorization focuses on such issues as the number of hours per week welfare recipients should be required to work, the definition of activities that should constitute working (the extent, for example, that participation in training or education programs should count toward work requirements), and the discretion that states should have for waiving either the 5-year lifetime benefits cap or other provisions. NCD is concerned that in resolving these matters, Congress and the Administration remember the issues facing recipients with disabilities and those with caregiver responsibility for spouses, parents or children with disabilities.

From the standpoint of some, accountability for performance is easier to define with welfare programs than in other areas. For them, the dramatic decline in the welfare rolls over the period since PRWORA was enacted is irrefutable evidence of success. But precisely because the rolls have dropped, current recipients probably include a disproportionate number of the most difficult and complex cases. In that light it should not be surprising that some 44 percent of current recipients are people with disabilities or people who have children with disabilities.[74]

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[73]PL 104-193, The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA).

[74]See AUCD's Legislative News in Brief: Vol. II, Issue 43 (December 2002) (studies referenced therein).

The methods that will be effective in helping as many of these persons as possible to enter or reenter gainful employment are often different from the methods that are effective with other definable subpopulations making up the welfare caseload. If Congress and the Administration are to succeed in restoring as many of these persons as possible to gainful employment, and avoid undue harm, including in many cases to innocent children, a number of distinctive issues must be taken into account.

1. REHABILITATION SERVICES

The legislation proposed last year by the Administration and adopted by the House provided that only three months of training or rehabilitation services can qualify as full-time work.[75] This is important because failure to meet the full-time work requirements is one of the grounds for financial sanctions under the law. NCD believes that three months is insufficient to meet the needs of recipients with disabilities and is unlikely to lead to employment.

In other areas, Congress has recognized that the vocational rehabilitation and placement of persons with disabilities often takes longer. The Ticket to Work and Self-Sufficiency Program under TWWIIA postulates ticket use for at least 24 months under most circumstances.[76] The Rehabilitation Act likewise avoids time-limited rehabilitation in favor of an outcome-based approach to providing services.

NCD does not contend that participation in countable rehabilitation services or programs should be unlimited or open-ended. We do recommend, however, that provision be made for an individualized assessment of each person or family, on the basis of which an appropriate time period for rehabilitation services should be determined. This assessment should include initial screening for disability and for vocational service needs for any individual identified as having a

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[75]HR 4737 (107th Cong. Second Session).

[76]See, generally, 20 CFR Part 411.

disability or likely to have one. Thereafter, the process would also include (in collaboration with the state vocational rehabilitation agency or other appropriate resources) formulation of an individual responsibility plan that includes the services and supports, goals and timeframes appropriate to the individual or family. In this way, the goals of independence and self-sufficiency will be better served than by imposition of arbitrary one-size-fits-all time limits.

To facilitate this goal, NCD recommends that reauthorization require that state welfare reform programs enter into cooperative agreements with state VR agencies or other appropriate entities to ensure that the necessary screening, services and expertise needed to rehabilitate recipients with disabilities will be forthcoming. Subject to determination by Congress of the proper allocation of responsibility for payment between welfare reform and VR, the reauthorization should also provide that support services, including accessible transportation, specialized child-care, job analysis, AT or job coaching, will be available where needed to allow recipients or caregivers to work. Once again, the language specifying this relationship and delineating the allocation of costs and responsibilities should be incorporated into both reauthorization statutes.

2. SANCTIONS

Under current and proposed law, people can lose TANF benefits in three ways. The desirable way is for them to obtain stable employment. The other two ways are by reaching the five-year lifetime cap, or as a penalty for failure to comply with program rules.

NCD has been unable to discover any data bearing upon the relative frequency of sanctions imposed on recipients with and without significant (including hidden) disabilities. Some attempt to gather such data is crucial to evaluating the performance of the system, and the reauthorization should include this among state reporting requirements.

NCD also recommends two other measures to avoid undue hardship. First, for that presumably small number of people who cannot be placed because of the fit between their severe disabilities

and the demands of the labor market, or who cannot be placed because the AT, accessible transportation or other specialized goods and services necessary for them to work are unavailable, NCD recommends that states be given authority to extend or waive the five-year limitations period.

Second, NCD recommends that when people with disabilities are sanctioned or when they time out of eligibility, mechanisms for referral to the SSA be established. Anecdotal evidence suggests that a number of such persons, who were somehow referred to welfare rather than to SSI or SSDI, may potentially be eligible for benefits under one of the Social Security programs. Provision should be made to ensure that a disability determination is offered, unless the recipient refuses to apply.

3. HEALTH INSURANCE

A final consideration relates to an issue of unique importance to many welfare recipients with disabilities. As Congress has recognized through provisions in a number of laws, loss of health insurance, especially Medicaid, represents one of the most significant work disincentives confronting people with disabilities. The temporary Medicaid coverage provisions of TANF must take this into account by ensuring continued Medicaid (or SCHIP for children) eligibility for a reasonable time, until private-sector coverage can be obtained through employment. In the case of persons who are uninsurable in the private sector, or who work for firms that do not provide a health insurance fringe benefit, this ongoing public-sector coverage may need to be of long duration. Congress should provide for these contingencies in the reauthorization utilizing the Medicaid buy-in model from TWWIIA or some other suitable approach.

Welfare reform rests on three interrelated premises: that returning people to work is economically good for the federal budget, that it is morally good for the recipients and that former welfare recipients can be assisted to live independently and with dignity. The issues raised and suggestions made in this chapter are predicated upon these values. For those who

believe (particularly as welfare reform prepares to enter its second phase) that success must involve more than simply purging the rolls, we believe these recommendations will contribute to an effective and humane process.

Housing

As reflected in remarks by President Bush quoted at the beginning of the Department of Housing and Urban Development's (HUD) 2003-2008 Strategic Plan, housing is central to the American dream.[77] HUD's involvement in almost every major social and public policy initiative through successive administrations also reflects this fact. In every major policy area—from the success of the community-based alternatives (or *Olmstead*) initiative, to the distance and difficulty of traveling to and from work, to the amount of discretionary income left for meeting personal goals, to the quality of education available for one's children–housing is paramount in all our lives. But perhaps no group faces housing challenges as acute and pervasive as Americans with disabilities do.

1. HUD'S STRATEGIC PLAN

The HUD FY 2003–2008 strategic plan lays out a comprehensive national agenda for housing policy, including initiatives reflecting the relationship between housing and other administration priorities.

To what extent does the plan address the barriers to affordable, accessible and safe housing facing Americans with disabilities? While many of the plan's goals and objectives will benefit most people, we feel the strategic plan fails to address a number of barriers specific to Americans with disabilities, which if unaddressed may substantially limit its value for this population.

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[77]Remarks of President George W. Bush on June 17, 2002, quoted in FY 2003–FY 2008 U.S. Department of Housing and Urban Development Draft Strategic Plan (November 12, 2002) (http://www.hud.gov/offices/cfo/reports/cforept.cfm).

(a) AFFORDABLE HOUSING

Increasing the overall housing supply should do much to improve affordability for most people, but will do little to bring that goal closer for many low-income Americans with disabilities. Only if the number of accessible housing units is steadily and significantly increased, and only if the economic conditions affecting this population are fully taken into account, can equal housing ever be achieved. For instance, in an effort to expand housing affordability, HUD proposes to use Section 8 vouchers (formerly designed for rent payment) to facilitate home ownership for 12,000 families by 2008. This goal is modest enough, but strikingly, though people with disabilities constitute one of the major Section 8-recipient subgroups, the plan contains no indication of whether or not the department expects them to be a focus of this home ownership initiative, or if so how it intends to incorporate them.

Outreach to this group is not self-evident. To the degree that a potentially significant portion of Section 8 voucher users may also be receiving benefits or services under other means-tested federal programs, effective use of Section 8 to facilitate home ownership may require attention to the income and resources limitations of Medicaid, SSI or other programs. While HUD's strategic plan is not necessarily the place for exploration of these intricacies, some recognition of the existence of such problems would be reassuring. Otherwise, as with so much else in the strategic plan, this commitment emerges as a succession of admirable intentions, unsupported by much detail or by clear awareness of the resource and cross-program issues involved.

More broadly, for the NFI's commitment to community-based living and to the implementation of the *Olmstead* decision to succeed, the supply-and-demand equation for accessible housing is likely to grow dramatically more acute. The strategic plan cites laudable cooperation between HUD and HHS in support of the *Olmstead* transition process, through technical assistance and housing vouchers. But the plan lacks any apparent overview or global vision concerning the likely number of accessible housing units our nation will need to bring the costs and supply of

accessible housing into balance. Also missing from the strategic plan is any clear notion of how our nation will create those needed housing units.

In determining the amount and type of accessible housing needed over the next generation, national policy should embody the principle that people with disabilities can expect the same choices in housing at essentially the same feature-for-feature cost, the same premiums for location and the same tradeoffs as anyone else. Accordingly, NCD recommends that the Administration adopt, with timetables, a goal that the supply and variety of accessible housing for those who need it shall be proportionally equal to the overall housing supply for the population as a whole. Put another way, if demand for housing in the nation is estimated to exceed demand by 5 percent, then the supply of accessible housing should likewise not be more than 5 percent short of the anticipated demand.

(b) HOME OWNERSHIP

Recognizing the 20–25 percent disparity between home ownership rates for people from culturally diverse backgrounds and non–culturally diverse Americans, and between upper- and moderate- or lower-income citizens, the HUD plan includes the goal of increasing and equalizing home ownership. Few goals could be more worthy. Yet again, the plan largely fails to address the unique barriers to home ownership facing so many Americans with disabilities, or the outreach issues involved in ensuring that home ownership initiatives reach them, or the resource needs of such a commitment.

In a letter to the Secretary of HUD, December 13, 2002,[78] NCD sets out in detail our concerns in this and other regards. For the moment, we note our belief that HUD must resolve a fundamental contradiction: whether or not its mainstream programs for home ownership are intended to extend to people with disabilities (in which case the various outreach, cross-programmatic and

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[78]NCD letter to the Secretary of Housing and Urban Development (December 13, 2002) (currently available at http://www.ncd.gov/newsroom/correspondence/martinez_12-13-02.html).

other unique issues must be addressed in program design), or promoting home ownership for this population is the province of specialized or narrowly targeted programs (in which case the resource needs and outcome measures applicable to these initiatives should be carefully and clearly addressed). If HUD agrees that homebuyers with disabilities should be served through its general programs, then planning must take the concerns and circumstances of people with disabilities into account. But if, despite the recommendation of NCD and the disability community to the contrary, HUD concludes that specialized programs represent the best vehicle for solving the problem, then the gross inadequacy and underfunding of these small programs must be acknowledged and remedied.

A related gap has to do with HUD's research on lending and credit practices. HUD reports some significant differences in the amount and timeliness of information disclosed to borrowers from culturally diverse backgrounds and indicates that among borrowers with identical financial profiles, those from culturally diverse backgrounds tend to receive smaller loans. HUD does not indicate whether or not it has sought to gather comparable data for borrowers with disabilities, or for that matter how it would approach the methodological issues associated with collecting such data for a low-incidence, geographically dispersed group.

In a similar vein, measuring the efficacy of home ownership programs for people with disabilities is made more difficult by the fact that the strategic plan includes neither information about current levels of home ownership among this population nor any indication of what percentage of improvement HUD would deem satisfactory. Without baseline numbers or measurable goals, accountability for performance becomes much more difficult to assess. Therefore, as a basis for determining the effectiveness of its programs in this area, NCD recommends that HUD incorporate in its strategic plan baseline data, timetables and goals for home ownership by persons with disabilities comparable to the goals it has established for other definable population subgroups.

2. CIVIL RIGHTS

Ensuring equal opportunity is the strategic goal that raises perhaps the greatest number of issues specific to people with disabilities. While HUD's proposals are valuable, they fall short of addressing the specific data collection, coordination and enforcement issues that would make the greatest difference for Americans with disabilities.

HUD has three disability civil rights laws to enforce: Section 504 of the Rehabilitation Act, the Fair Housing Act Amendments of 1988 and ADA.[79] In coming to its enforcement responsibilities under these laws, HUD has a long and disappointing history to overcome. Not until 1988, a full 15 years after the enactment of Section 504, did HUD promulgate regulations to enforce the law. More recently, as documented in NCD's Reconstructing Fair Housing report,[80] resources for enforcing civil rights laws declined dramatically during the 1990s, and major problems of complaint processing, inter- and intra-agency coordination, information dissemination, management and record-keeping have remained unresolved, often for years. Finally, the Housing and Community Development Act of 1992 charged HUD to carry out a Section 504 self-evaluation by 1995, but as of this date, that has yet to take place.

Without a clear sense of the strengths and weaknesses of its own commitment to civil rights, it should come as no surprise that many in the disability community question the capacity of the department to monitor the civil rights compliance of others. Aware of this loss of faith in HUD,

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[79]The Americans with Disabilities Act of 1990 (ADA), particularly Titles II and III, 42 USC Secs. 12131 and 12181; the Fair Housing Act Amendments of 1988, 42 USC Sec. 3601 et seq.; and Section 504 of the Rehabilitation Act of 1973, as amended, 29 USC Sec. 794.

[80]Reconstructing Fair Housing, Note 1, supra. Also, Oversight Hearing: Fighting Discrimination Against the Disabled and Minorities Through Fair Housing Enforcement, House Committee on Financial Services, Subcommittee on Oversight and Investigations and Subcommittee on Housing and Community Opportunity (http://financialservices.house.gov/hearings.asp?formmode=detail&hearing=147); and see NCD letter (July 29, 2002) (currently available at http://www.ncd.gov/newsroom/correspondence/kelly_07-29-02.html).

NCD has continued to look for the responsiveness and willingness by HUD's new management to engage in dialog and react seriously to our findings and concerns. It is against this background that we comment on the failure of the draft strategic plan to thus far address the persistent issues of discrimination and civil rights law enforcement with the depth and scope their complexity and severity warrant.

(a) COMPLAINT PROCESSING

In the strategic plan, HUD points to its successes in reducing the number of "aged" complaints in its inventory and to its targets for further reduction each year. NCD had expected that HUD's discussion of its plans in this area was accompanied by comparable attention to the ways the backlog will be reduced and to the quality of outcomes complainants and respondents can expect to achieve. The percentage of adjudicated complaints in which "reasonable cause" has been found has declined over the past three years. HUD's strategy for reducing complaint backlogs cannot be evaluated unless the possible reasons for this outcome variability are explored, and unless the possibility of a connection between backlog reduction and outcomes quality is studied.

The techniques used to evaluate quality of enforcement and adjudication in the area of disability may need to be quite different from those applicable in other areas of civil rights jurisdiction. Likewise, the issues may be considerably more complex and varied. For example, only in the disability area, where compliance with design guidelines is an issue, could the law be violated long before the potential buyer or renter ever comes into contact with an architect, seller, realtor or other housing industry participant. Similarly, the mindset of those who discriminate in housing on the basis of disability is typically very different from those who discriminate on other grounds. Have complaints of housing discrimination on grounds of race or ethnicity ever been based on the misguided beliefs by real estate professionals that members of ethnic or racial minorities might be unable to climb stairs, escape fires or understand rules?

The question must be asked, therefore, whether or not HUD's strategic plan or other official pronouncements reflect an understanding of the varying, complex and unique issues affecting its implementation of disability civil rights laws or embody a commitment to developing the resources and methodologies required to address them?

(b) ENFORCEMENT

In light of these complexities and of HUD's history of under-enforcement, Objective 3 under the strategic plan's equal opportunity goal raises more questions than it answers and gives all too little ground for confidence. That objective expresses HUD's belief that enforcement of Section 504 will result in an increase in the availability of accessible housing. Disappointingly absent from the plan is any indication of the extent to which Section 504 has or has not achieved that goal thus far, or of the relationship between various proposed enforcement and public awareness strategies and expected increases in accessible housing supply.

Judging from the strategic plan, HUD has little information on the current availability of or unmet need for accessible housing, few specific numerical or percentage goals for anything but token levels of increase, and few tools for measuring the impact of its enforcement choices and educational activities. While HUD does embrace specific goals for accessibility of newly constructed HUD-assisted units, and while the agency also embraces measurable targets for assessing the penetration of its public awareness and educational efforts, the number of accessible new units postulated cannot possibly come close to meeting the growing demand. Nor does HUD explain how, if at all, it plans to measure the impact of its fair-housing information-dissemination activities upon the behavior of builders, brokers, lenders, agents, landlords or others.

In this connection, NCD understands that HUD intends to continue major enhancements in training and technical assistance outreach to the real estate community, including issuing contracts that will facilitate the conduct of accessibility seminars at a variety of real estate

industry events. While there is no question that increased education and awareness are critical components of a comprehensive enforcement strategy, the assumptions underlying these new initiatives might warrant further discussion. Perhaps the first question to ask in this regard is: If lack of awareness of accessibility and related legal requirements on the part of the real estate industry is a major cause of inadvertent discrimination or of insufficient affordable and accessible housing (as HUD appears to believe it to be), why, after at least 15 years of enforcement by HUD, does such lack of knowledge remain so widespread? Apart from the amounts of time and money HUD has spent, what has been right and wrong with HUD's outreach efforts over the years, and to what extent do these new initiatives build on what has worked and eliminate what has not? Before investing in further potentially unproductive outreach strategies, does HUD have any inkling of the answer to these fundamental questions?

A further concern in the enforcement area relates to HUD's plans for initiating and investigating pattern and practice and systemic discrimination cases, and for referring such cases to DOJ. Precisely because the strategic plan acknowledges the difficulty and complexity of such cases, it is all the more important for HUD to articulate clear and accountable criteria for identifying, prioritizing, investigating and referring such cases. Though not part of a HUD document, DOJ must also clarify its role and expectations regarding fair housing enforcement, beyond enforcement of hate crimes or other cases involving violation of criminal law. For answering these key questions, NCD recommends that HUD and DOJ jointly develop clear guidelines for determining what discrimination cases, other than those involving criminal conduct, will be referred to DOJ for further action, and what policies DOJ will follow in litigating and disposing of such cases.

(c) ORGANIZATION

One of the problems with HUD's civil rights enforcement has been the frequent departmental reorganizations that have contributed to the loss of a focal point for the civil rights effort. NCD believes that strengthening of the department's Office of Fair Housing and Equal Opportunity

(FHEO) would represent a major step in restoring vigor to the civil rights effort. Beyond requesting additional funds for FHEO as the Administration has done in its FY 2003 budget request, NCD recommends that FHEO be elevated to a position reporting directly to the Secretary of HUD, possibly as part of the general counsel's office, and that additional steps be taken to demonstrate and sustain an ongoing commitment to civil rights at the highest executive levels.

(d) FUNDING

NCD has never made the glib assumption that funding automatically equates with results. But in HUD's case, given the steady attrition in personnel and other resources for civil rights enforcement over the past decade (an attrition not yet adequately reversed), we believe that such measures as revitalization of the FHEO, enhancement of the speed and quality of complaint investigation and disposition, improved management and oversight of contractors, and gathering of information and coordination with other agencies cannot be achieved without major resource infusions.

Under current budgetary conditions, all agencies and functions must take their proportional hit. The question however is, What is proportional? If HUD's civil rights efforts had been adequately funded over the past decade, that would be one thing. But in view of their underfunding over those years, to treat them with the same budgetary analysis as programs that were well-funded only compounds and worsens the neglect and failure of the past.

(e) VISITABILITY

Short of full accessibility, the concept of "visitability" has gained prominence as a strategy for enabling people with disabilities to enter and function within many homes. As discussed in detail in last year's status report, visitability involves incorporating a number of basic design features

that will allow most people with disabilities at the very least to get through the door and use the bathroom.

Important in its own right, visitability is also an example of a strategy that did not exist when the rules governing enforcement of the three disability-related fair housing laws were developed. As such, it remains unclear where visitability fits in the assessment of architectural or building practices, or whether HUD or not takes it into account, through the award of bonus points or otherwise, in determining compliance by the developers of federally assisted housing with requirements concerning the percentage of units that must be accessible. HUD should provide clarification on these issues, ensure the inclusion of visitability in its technical assistance where indicated, and review and report on the need for and the possibility of its inclusion in future legislation.

(f) ACCESSIBILITY TO PERSONS WITH SENSORY DISABILITIES

Under current law, 5 percent of federally assisted new housing must be accessible as that term has traditionally been understood. Less well known is that 2 percent of such units must be accessible to persons with sensory disabilities. HUD needs to clarify the meaning of this requirement, disseminate information to the building community and its own enforcement staff, and incorporate the requisite standards in key regulations.

Noting that we would never allow home thermostats to be placed so high on walls that people using wheelchairs could not reach them, last year's report discussed the analogous ways we are allowing most new homes to become increasingly inaccessible, and in many cases dangerous as a result, to people with visual impairments. Thermostats, built-in kitchen appliances and other features of the modern "smart house" need not be designed for operation solely with digital or touch-panel controls that people with visual impairments or people with other disabilities cannot access or use. Yet, more and more, according to anecdotal reports, homes are being designed or

remodeled in just this one-size-fits-all way, despite the existence of simple, inexpensive design strategies for avoiding these situations.

Accordingly, NCD again calls upon HUD to address these matters with the urgency that our changing demographics and our commitment to community living warrants. For many people with sensory, motor or cognitive disabilities or multiple chemical sensitivities, and for many people with conditions that limit various major life activities but that do not cross the legal threshold of disability, the design and operation of household appliances and controls may often be a major factor in determining whether or not and with what assistance they can perform the self-care activities necessary to remain in, or return to, their own homes.

If the Administration is thorough in its approach under the NFI, attention to issues such as these can go a long way to maximizing the accessibility of America's housing stock, new and old, in the coming years. Few strategies could involve less cost per unit or could yield so much benefit per dollar spent.

3. SYSTEMIC STRATEGIES

Civil rights enforcement, training and technical assistance, and incentives through federal funding are all vital elements of a comprehensive housing strategy. Yet the key question remains whether or not these current measures, when implemented with the coherence and vigor they deserve, can by themselves generate the amount of accessible and affordable housing America will need as the baby boom crests the wave of age in a society that cannot afford, and increasingly does not want, to institutionalize them. In no area do issues of disability and of aging fuse so seamlessly as housing.

This being so, the basic question for any HUD strategic plan is not how this or that program will be administered, but a far more profound one. How much accessible housing does America need? What proportion of new or existing housing needs to be accessible? What is the best

means of bringing this about? How can government, consumers and the private sector best cooperate to do it? The challenge for HUD, as suggested above, is to demonstrate that it grasps the nature and enormity of these questions.

Without a strategic plan for anticipating and meeting this rising tidal wave of need, HUD must at least begin to marshal the best thinking and best practices that can be brought to bear from around the country. NCD recommends that a high-level national commission be appointed by the President and Congress to study America's housing needs over the next generation and to make detailed recommendations for how they can be met. Deliberations of the commission should include ways that the variety of federal involvements in the private housing market can be used, noncoercively but effectively, to encourage accessibility; how disclosure and lending practices can be modified to raise awareness of and clarify informational requirements pertaining to accessibility; how the significant tax subsidization of residential real estate can be refined to promote greater accessibility; how contractor, architect and other licensing requirements can be updated to ensure full awareness of contemporary design possibilities and available materials; how intergenerational or cooperative housing ventures can be used to enhance accessibility and community participation; and how coordination with other systems can be structured to maximize the goals of community living and aging-in-place.

Transportation

1. AIR TRAVEL

Air travel has continued to change rapidly over the past year, as new security screening procedures and personnel have been put in place. With major new baggage-screening initiatives and other measures still coming into effect, the pace of change is likely to continue at a high rate.

(a) TRANSPORTATION SECURITY

No issue has commanded so much attention as airport, air traveler and aircraft security. Fortunately, while growing tension between personal liberty and security have come to the fore in debates over public policy in many areas of our lives, such tension in air-travel security has been substantially avoided for people with disabilities by the combined efforts of the Transportation Security Administration (TSA) and the disability community.

NCD commends the Department of Transportation (DOT) and the TSA for incorporating issues of concern to passengers with disabilities into its training curriculum for airport security screeners, and for its outreach to the disability community.[81] In particular, the TSA's fact sheet on security requirements and accessibility requirements has provided valuable information and helped to preserve awareness that these two goals need not be incompatible.[82] The Department's Disability Coalition, which held its initial meeting in November 2002, appears to represent an

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[81]Remarks of Gale Rossides, at the Department of Transportation, Transportation Security Administration's Disability Coalition Meeting (November 13, 2002) (http://www.dot.gov/affairs/111302spb.htm).

[82]New Horizons—Information for the Air Traveler with a Disability (FAA Office of Civil Rights, 2002) (http://www1.faa.gov/acr/dat.htm#compliance). Compare Fact Sheet: Steps Taken to Ensure New Security Requirements Preserve and Respect the Civil Rights of People with Disabilities (USDOT, October 29, 2001).

extremely promising forum for ensuring continued flow of information and effective communication of concerns in this vital area.[83]

Attention now focuses on how these initiatives will be continued. With the impending transfer of the TSA from DOT to the newly created Department of Homeland Security (HSD), NCD is concerned to know what measures will be taken to ensure that the mechanisms thus far put in place will be preserved and enhanced, and to ensure that continuity will exist with respect to current ongoing efforts.

As discussed by TSA and DOT officials at the November 13, 2002, coalition meeting, training materials and operational guidelines are still under development in a number of key disability-related areas, including access for nonticketed persons to gate areas. Additional subjects appropriate for coalition consideration remain to be addressed, including locating and retrieving of screened bags by passengers with visual impairments who cannot find them after inspection or who are not informed when their bags are taken aside for hand search. (The Air Carrier Access Act is discussed further in section c, below.)

The ability of TSA to continue addressing issues of concern to people with disabilities after moving to the new department will remain crucial in order to meet new challenges and vindicate the work already done. Because the issues of antidiscrimination and civil rights protection by the HSD entities raise questions going beyond transportation, we will return to this discussion in Chapter 13.

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[83]Minutes of the Transportation Security Administration's Disability Coalition Meeting (November 13, 2002) (see Note 81, supra).

(b) FOREIGN CARRIERS

One area of ongoing concern is the security procedures used by foreign air carriers. Last year's report called for DOT to complete negotiations with foreign flag carriers serving the United States on procedures to ensure their compliance with the Air Carrier Access Act (ACAA). Subsequent development of domestic security procedures, including requirements that apply to foreign carriers, makes it all the more urgent that negotiations or rulemaking proceed with international carriers and regulators aimed at ensuring that accessibility keeps pace.

NCD is concerned that such initiatives could fall between the cracks, not coming within the jurisdiction or priorities of DOT or the HSD, or alternatively becoming the subject of competing jurisdictional claims between them.

(c) AIR CARRIER ACCESS ACT

In the current environment it is understandable how many issues of airport management, air carrier practices and security screening methods can be subsumed under the rubric of security. Various impositions, intrusions and regimentations that would once have been impermissible are now accepted and indispensable elements of safe travel. But the discrimination that gave rise to the ACAA and to DOT's technical assistance and enforcement activities around the law has not ceased to matter or to exist just because security has asserted itself as our primary concern.

Considerable fear exists that while essentially preempting the regulation of a variety of airport and air-carrier practices, the HSD may not have the resources to vigorously enforce ACAA priorities. Implementation of the ACAA is a civil rights jurisdiction different from and independent of ADA, Section 504 or any other provisions broadly known across the Federal Government. With expertise likely divided between the HSD's TSA and the Department of Transportation's Aviation Consumer Protection Division, sustained and focused effort and

effective coordination will be required if the ACAA is not to be relegated to confusion and insignificance.

NCD is therefore concerned to know how and by whom the ACAA will be administered, enforced and monitored once responsibility for air travel is divided between DOT and the HSD. How will the line between security jurisdiction and accessibility jurisdiction be drawn or be crossed, and who will be making the key decisions?

NCD has been very heartened by a number of ACAA-implementation steps taken by DOT in the past year, including most notably the support of the Aviation Consumer Disability Hotline through which complaints can be made and recorded.[84]

In August of 2002, DOT and NCD entered into a memorandum of understanding (MOU) whereby DOT provided NCD with the resources to assist with a continuing collaboration on ACAA implementation. The MOU provides that over the course of the year, NCD will work with the airline industry and the disability community in developing guidance on service animals, on oxygen users and on access for air travelers who are deaf and hard of hearing, and to assist DOT with its ACAA forums.

Nevertheless, even without regard to the problems posed by reorganization, NCD has a number of concerns about follow-through on other ACAA initiatives discussed in last year's report. Pending clarification of how responsibility for the law will be allocated, though, detailed review of these concerns would serve little purpose. Suffice it to say for the present, decisions like that of the OMB to cease the air traveler satisfaction survey process are alarming.

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[84]The toll-free number for the Aviation Consumer Disability hotline established in August 2002 is (800) 778-4838 (voice), (800) 455-9880 (TTY). See http://airconsumer.ost.dot.gov/hotline.htm#navskip.

An additional concern in this connection relates to the impact of major airline personnel cutbacks on services and accommodations for passengers with disabilities. As financially strapped air carriers and airport managements cut back on employees and contractual services, a number of anecdotal reports reaching NCD suggest longer waits for assistance, unavailability of escort personnel where needed and other difficulties. NCD recommends that DOT clarify the responsibilities of carriers, airport managers and contractual airport service providers for providing various forms of assistance to passengers with disabilities during the embarkation and disembarkation phases of their trips, in retrieving checked baggage, in moving from place to place and in related areas.

(d) AIRPORT TICKET MACHINES

One area of particular concern in this regard has to do with the switch by many carriers at many airports from ticket agents to ticket machines at check-in counters. For people who can use them to print out boarding passes, these machines save time and avoid long lines, but for many passengers with disabilities, including persons who are blind or persons who have motor or cognitive impairments, these machines are inaccessible and result in delays of long and uncertain duration in lines of people waiting to be served by a dwindling number of counter agents.

It is NCD's belief that the inaccessibility of these machines does not derive from any technical or economic barriers to making them accessible. ATM machines, mass transit ticket and fare machines and kiosks of many kinds have been made accessible to users who are blind, and such machines are widely deployed at costs now essentially identical to those of conventional machines. The apparent failure of the new generation of airport ticket machines to incorporate such accessibility features appears rather to arise from indifference alone.

NCD recommends that DOT and DOJ address the accessibility issues posed by these machines and by other new customer-service technology. With respect to the airport ticketing machines, the initial question may well be the jurisdictional one as to whether they are covered by the

ACAA, ADA or both. Depending on the answer, DOT and DOJ should move expeditiously to require that they incorporate already widespread accessibility features now common in the ATM and point-of-sale machine sectors.

2. TRANSPORTATION ACT REAUTHORIZATION

Most commonly called the federal highway bill, the Transportation Equity Act for the 21st Century (TEA-21) covers almost all surface transportation in our nation.[85] TEA-21 is scheduled for reauthorization in 2003.

Although not always obvious, many of the provisions of TEA-21 affect Americans with disabilities in direct and highly specific ways. NCD will offer its experience and perspectives on many of these issues at appropriate congressional hearings as the bill takes shape. For the time being, though, several key concerns should be noted.

(a) EQUITY

As the very name of the law suggests, transportation policy involves complex and constantly shifting questions of equity. In a nation where the open road, the right to drive and the availability of automobiles are axiomatic, many of the challenges and tradeoffs in transportation policy may not at first glance be obvious. Suffice it to say, many Americans, including older Americans and many people with disabilities, are unable to drive, because of the nature of their disabilities or for legal reasons, or because of practical problems in the transportation infrastructure ranging from cost of vehicle modifications to lack of accessible parking spaces or of gas station attendants willing to pump gas. In addition, many people with and without disabilities living in proximity to public transit choose not to drive, and many more would make that choice if given the option.

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[85]PL 105-178, The Transportation Equity for the 21st Century Act of 1998 (TEA-21).

In grappling with the host of issues involved, the reauthorization occurs at a very different time for Americans with disabilities than existed when TEA-21 was enacted five years ago. The *Olmstead* decision and the NFI have emerged in the few short years that have elapsed since TEA-21 was passed.

(b) *OLMSTEAD*, NFI AND TRANSPORTATION

For the nation to shift from institutionalization to independent and community-based services, community-based transportation resources must be adequate in amount and flexibility to meet the needs for participation by many persons with disabilities and older persons. Accordingly, NCD recommends that in the reauthorization, Congress require the involvement of state and local transportation agencies in *Olmstead* planning processes. The NFI budget authorizations and appropriations for pilot demonstration transportation projects and for matching grants to nontraditional providers or planners should also be incorporated into the new law.

The practices and priorities of paratransit systems must also be re-evaluated in light of contemporary needs, with a view to ensuring that these programs maximize the goals of community in supporting both *Olmstead* and employment goals for Americans of all ages with disabilities.

Two examples may be useful in clarifying what we believe is necessary and for demonstrating key connections between transportation and other public policy initiatives. The first is drawn from the employment sector. The current law contains provisions for providing support for transportation for people entering or returning to employment through welfare reform programs, and to facilitate certain transportation to and from work for other low-income persons.[86] Whether through paratransit or other means, these provisions continue in effect, but to be responsive to the needs of persons with disabilities the method adopted must incorporate sufficient flexibility to

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[86]See PL 105-200.

allow for use of accessible vehicles and, where appropriate, for other technology or necessary support services.

The second example brings us to *Olmstead* initiatives. Because effective *Olmstead* plans will focus on preventing institutionalization as well as on reversing it, many people who are the object of the effort will not necessarily yet have disabilities within the meaning of the law. Frail elderly and other at-risk individuals will have a variety of needs, including for transportation. Unless transit systems carefully evaluate eligibility criteria and procedures, overly technical definitions of who qualifies for paratransit or other specialized *Olmstead*-related services based on legal status, age or other seemingly objective criteria may result in denial of service to people who badly need it in order to remain in their homes and communities.

For this reason, NCD recommends that the statutory criteria for paratransit eligibility be designed with a view to requiring local transit agencies to utilize standards established by state and local *Olmstead* plans in determining eligibility for service. These standards are likely to differ from place to place, but only by acknowledging and respecting such differences can the goal of integrating an overarching national policy with varying local needs and conditions be achieved. Other paratransit issues will be discussed in section d, below.

(c) EMERGING ISSUES

In its continuing efforts to develop standards and guidelines implementing the accessibility requirements of ADA, the U.S. Access Board has done a great deal to bring issues of pedestrian access and safety to public attention. Pursuant to the work of a broadly representative advisory committee, the Board proposed for public discussion rights-of-way guidelines in June 2002.[87] With new developments in urban design and traffic engineering, ranging from "blended transitions" (which dispense with curbs or curb-cuts between sidewalks and streets) to traffic

[87]http://www.access-board.gov/rowdraft.htm

roundabouts (intended to facilitate the uninterrupted flow of vehicular traffic), pedestrian safety has emerged as an issue not only for people with disabilities but for everyone.

At the same time, quality-of-life considerations have led to a parallel recognition that, for example, placing a light rail stop near an industrial park does little good if a six-lane highway must be crossed without benefit of stop signs in order to get from one to the other.

The ADA included provisions for requiring detectable warning edges on mass transit platforms and in hazardous pedestrian areas, but implementation of these safety precautions, especially in connection with mass transit platform edges, has been slowed by disputes over the precise methods and materials to be used, cost considerations and a variety of other factors. Technological advances in audible or vibratory traffic signals also remain to be systematically implemented, though a number of communities have taken the initiative, adopting innovative plans and technologies without waiting for federal guidance, and though important research is under way.

TEA-21 contains provisions for research in a number of related areas, including such other exciting frontiers as smart highways. DOT has also included some extremely valuable requirements in its manuals.[88] To ensure that the momentum in these areas continues to build, and to avoid any uncertainty over the jurisdictional boundaries between the Transportation Act and ADA, NCD recommends that the new law should include requirements and funding authorization for continued research in all the subjects noted in this section—for pilot and demonstration projects in various environments around the country, and for evaluating and disseminating results—and provisions for incorporating the most successful technologies and strategies into our overall transportation infrastructure.

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[88]Federal Highway Administration manuals published over the past few years have begun to address questions of pedestrian safety with new focus. TEA-21 also contains a number of provisions and grant opportunities bearing on these issues. Links to a variety of relevant resources are available at http://www.acb.org/pedestrian.

Though many of these issues are of greatest concern to Americans with disabilities, their significance is not limited to this population. Accordingly, new linkages must be forged between the kinds of research and policymaking authorized under ADA and the parallel efforts being made under the Transportation Act. At a minimum this cooperation should entail input from people with disabilities or those with expertise in the relevant transportation issues into the design of major transportation research projects and experiments. Backed up by improved coordination between DOT and DOJ, the law should also require a clear recognition that ADA applies to transportation systems, policies and vehicles in ways going well beyond the familiar issue of accessibility of intercity buses. Such coordination also requires the realization that Section 504 applies not only to accessibility of vehicles, design of stations and level of services, but also to the effects of new transportation systems on related access issues such as the ability of pedestrians with disabilities to safely board or disembark.

Similarly, highway projects can no longer be designed with only traffic flow in mind. We would not rest quietly if a new federally funded auditorium opened without accessible seating, or if the monorail carrying people to and from it contained no wheelchair lifts. Yet we continue to require people with disabilities to brave dangerous traffic conditions and to undergo other privations and risks in order to benefit from what their tax dollars have helped to build. We stand on the brink of a great revolution in transportation, one that may change our lives no less than the Internet revolution in communications has. But as the Internet has increased the opportunities for effective communication immeasurably, so can the transportation system of the future make movement from place to place a safer, more efficient and less stressful process for all.

(d) PARATRANSIT

Reports from around the country indicate that many public transit agencies are making greater use of conditional eligibility. NCD recommends that DOT should comprehensively review this practice to make certain that conditional eligibility does not undermine the rights to paratransit services established under federal law.

A related issue concerns the right to next-day service. Two cases on this subject are now making their way through the federal courts.[89] NCD commends DOJ on behalf of the United States and DOT for filing a brief in the U.S. Court of Appeals for the Second Circuit supporting the lower court finding that next-day service must be provided to all eligible persons.

As local and state budgetary problems lead to cutbacks in fixed-route mass transit service, more and more people with disabilities are likely to need paratransit services owing to increased difficulties, ranging from longer periods waiting in extreme hot or cold to increased personal security concerns at isolated stops. Transit agencies are likely to make increased use of trip-eligibility criteria or to try to impose longer advance-notice requirements for trip requests. Under these circumstances, whatever the TEA-21 reauthorization ultimately specifies, DOT must be all the more vigilant in maintaining the fairness and effectiveness of paratransit while maximizing its flexibility in dealing with new needs and potential new customers.

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[89]e.g., Amicus Brief of the *U.S. Department of Justice in Liberty Resources Inc. v. SEPTA* (Civil Action No. 99-4837, E.D.Pa. 2001) (currently available at http://www.libertyresources.org/advocacy/septa-brief-nextday.html).

Assistive Technology and Telecommunications

1. ASSISTIVE TECHNOLOGY AND THE NEW FREEDOM INITIATIVE

Since the unveiling of President Bush's NFI, Administration proposals in the area of disability services and policies have included a number of programs with important AT components. This attention to AT reflects awareness that technology is central to the efficacy of many programs. Yet inevitably, addressing the issues of technology on a program-by-program, statute-by-statute basis is bound to result in inconsistencies, gaps and unintended barriers to the kind of coordination so necessary for far-reaching policy initiatives such as the NFI to achieve their goals.

Despite concerted efforts to attain greater coordination among federal agencies and programs, people with disabilities continue to report persistent barriers in their efforts to obtain, use and benefit from AT.

NCD believes that AT should be a central component of every service system and program in the disability area and should be made available as a front-line resource for all entities and programs receiving federal funds, covered by federal antidiscrimination laws, or engaged in activities on behalf of the Federal Government. Put another way, federal policy should unequivocally state that, while not the modality or strategy of choice in every case or for every individual, AT must be available in every situation where it could prove useful in meeting program goals.

From the standpoint of any commitment to accountability for results, we believe that prioritizing AT devices and services will yield the most positive results and outcomes. Yet law alone cannot establish this emphasis. Only with a philosophy of optimization can the commitment to full utilization of AT yield the desired benefits. For example, today the laws governing our service

systems generally do not require optimization of educational or vocational potential.[90] The laws require only that services be sufficient to achieve what may be called minimal results. We urgently need to adopt an approach that measures outcomes and defines appropriate services by highest potential and capacity rather than by deficits or needs.

The sea change represented by such a shift from a deficit-based to a potential-based model can and should begin with a thorough review of our policies toward AT. Ideally, the baseline for this inquiry should be the innumerable ways in which government supports development and use of many types of technology throughout mainstream society. Because people with disabilities have less access to the technological tools for education, employment and community life, and because barriers such as the pervasive requirement to demonstrate a high level of individualized need stand in the way of technological equality, our overall approach is greatly in need of reform. Put another way, the question should never be, Can this individual with a disability prove an individualized need for technology of a given sort? The question should be, If a person without a disability can routinely expect to have access to a particular kind of technology for performing particular functions, why should similarly situated individuals with disabilities not expect the same level of access, where means for attaining it exist?

Some will argue that such a commitment will be too expensive because it would result in the provision of AT devices and services to more people and in more settings than current law and practice require. Recognizing that such an approach raises many questions, NCD proposes the use of a transparent method for carrying out the necessary cost-benefit analyses and related studies.

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[90]Although the IDEA Amendments of 1997 established more ambitious outcome goals for students with disabilities, the law essentially remains that individual students are not entitled to special education services that will maximize their potential, but only to services that will enable them to participate and perform adequately. See *Hendrick Hudson Central School District v. Rowley,* 458 U.S. 176 (1982). Similarly, in employment the RSA has taken pains to clarify that the law requires more than entry-level employment, but this has not generally been interpreted to mean maximization of potential for each individual. See RSA Policy Directive 97-04 (August 19, 1997); also 66 Fed. Reg. 4419 and 7250 (January 17 and 22, 2001).

In the past, many excellent studies have documented barriers to AT access and use by individuals with disabilities. But no study of which we are aware has attempted to systematically estimate the savings that would accrue to government or the tangible benefits to society from broad-based implementation of policies that emphasized the intensive use of AT to maximize individual potential and outcomes in education, employment and health. Therefore, NCD recommends that Congress and the Administration should establish a national commission to study not the already-known barriers to AT utilization, but instead the potential impact on existing programs, on people with disabilities and on government expenditure that can reasonably be expected to result through systematic and intensive application of technology.

Beginning from the premise that appropriate applications of technology, coupled with the necessary support resources, can improve educational performance, employment outcomes and career advancement and can reduce the costs of medical care and delay or forestall the need for institutionalization, we believe this potential can be reliably quantified and correlated with projected government savings in income-support as well as other programs. If the study yields the findings we foresee, then a serious national discussion about revising existing program models, redirecting funding or finding new sources of investment in AT can begin.

Neither the research nor the changes we believe it will produce can be effective if limited to AT, however. Without simultaneous and balanced attention to the accessibility of the mainstream transportation, communications and housing environments and infrastructure, AT by itself can accomplish only part of the job. Accordingly, the Commission must also address the costs and benefits that would accrue to government and to various private entities and institutions from systematic efforts to implement universal and accessible design practices. The complexities of such research are admittedly considerable, but using sophisticated, widely accepted econometric, sampling, interview, demonstration study and other research methods for deriving reliable data, the potential exists to shape the key public policy and resource allocation decisions that lie ahead.

Recognizing that industry and society's ability to incorporate accessible and universal design practices will involve many difficulties, NCD has undertaken to create a firm foundation for the discussion of barriers and strategies. NCD has issued an RFP for a study of the most widely reported barriers to accessible and universal design, with a view to documenting and analyzing the nature and extent of these obstacles.[91] When completed at the end of 2003, this research should contribute significantly to the policy discussion, to the practical ability of industry and consumers to respond to the opportunities created by accessible design, and to the work of the proposed national commission.

As important as these ongoing and proposed research initiatives are, they also herald a new approach to the formulation of an accountable, results-oriented public policy. If carefully conducted research demonstrates a high probability that investment in AT and accessible design will yield substantial benefits, the time will be right for considering where the resources necessary to make these investments can be found. If not, much valuable information to improve existing programs and approaches will still have been collected. The ultimate point here is simple. If policies are to be measured by their results, governmental accountability requires that the potential results of plausible alternatives to current policy also be seriously investigated. We are accountable for what we do not do as much as for what we do, especially where there is reason for believing that the impact of other approaches would be greater than those of current methods.

Recent discussion of national economic policy has focused on the question of whether or not higher short-term deficits resulting from tax cuts can be justified by their contribution to long-term economic growth. Whatever the answer, our public policy has often followed an investment strategy whereby tangible benefits would result in the long run. Indeed, we have followed just such an investment strategy with respect to mainstream technology, investing vast amounts of public and private resources in the belief that it will contribute to productivity of the economy and to quality of life. Let us at least gather the data to permit an informed determination on

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[91]Note 7, supra.

whether or not and how such a strategy can now be introduced for assistive and universally designed technology as well.

2. THE ASSISTIVE TECHNOLOGY ACT

The Assistive Technology Act of 1998 (AT Act, formerly known as the Tech Act)[92] was due to sunset last year. Pursuant to continuing resolutions, the program remains in operation but with termination still grimly facing it.

NCD believes that the AT Act has contributed significantly to improvements in technology utilization by a variety of service systems and to better technology access for many with disabilities. Moreover, without this program, a number of significant NFI initiatives (discussed below) will be placed in considerable jeopardy. For these reasons NCD recommends that the AT Act be reauthorized.

The AT Act supports a number of important activities, including protection and advocacy services for AT in the states and nationwide technical assistance, that would be jeopardized by its elimination. Also in great jeopardy are the state-based AT programs operating under this law. These programs have been able to introduce AT-related considerations into state policy and decisionmaking, often in ways that no other entity can do. Because the focus of these state-based entities is technology, rather than any one particular statute or agency, they have been able to address issues and participate in deliberations involving programs for people of all ages across the spectrum of state policy. While these state AT projects are relatively little known, the consequences of their demise will be large and visible.

At a time when states are imposing draconian program cutbacks to balance their budgets, a key and unique source of input to their deliberations would be lost. The costs of this loss for *Olmstead* planning, for brokering interagency coordination at state level, for outreach to

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[92]PL 105-394, The Assistive Technology Act of 1998.

employers, educators and people with disabilities about technology, and for other worthy goals will greatly outweigh the savings achieved by ending this small program with its large accomplishments.

Nor in the absence of these state AT programs is it clear how a number of Administration programs will be carried out. For example, the alternative financing program loan funds operating under Title III of the AT Act have been established and managed by these state AT Act projects, in conjunction with a variety of partners including not-for-profit organizations and banks. Announcement on December 26 , 2002,of an additional consumer AT loan initiative specifically directed to telework opportunities for people with disabilities further complicates the question of how these programs will be administered and monitored.[93]

Various proposals for preserving the AT Act resources have been offered. The AT Act as such need not be retained. What is necessary is that the substance, expertise and networks developed by these projects be preserved, both to facilitate implementation of new federal initiatives and to ensure that at a time of unprecedented state budgetary turmoil, the gains made through use of AT will not be unwittingly sacrificed.

3. TAX INCENTIVES

Because tax incentives lie at the heart of current government economic growth strategy, it is especially appropriate to ask whether tax policy can be more effectively used for economic advancement of people with disabilities.

While tax changes that successfully stimulate capital formation will likely help a wide range of commercial ventures, a number of the issues affecting the AT marketplace need to be addressed by more specific and focused provisions. As noted in Chapter 4, a recent GAO report concluded there is little evidence to support the effectiveness of current business tax incentives in increasing

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[93]Fed. Reg. Vol. 67, No. 248 (Request for Comment, December 26, 2002).

private-sector employment of individuals with disabilities.[94] Given what can only be described as the quirky provisions of each of the three major disability-employment incentives in current tax law, NCD is not surprised by GAO's findings. Moreover, GAO does not and cannot conclude that better designed, better publicized and more consistently administered provisions would be ineffective in enhancing employment of persons with disabilities.

Two examples will illustrate why the current disability and technology incentives require refinement. First, the Architectural and Transportation Barriers Removal deduction allows businesses to claim a tax deduction of up to $25,000 per year for removal of such barriers to the "elderly and handicapped."[95] Unfortunately the definition of what constitutes an acceptable barrier-removal activity predates ADA, and those guidelines have never been harmonized with the design requirements in the ADAAG. In addition, if one can get beyond the confusing standards, one finds that most of the barrier-removal activities covered by the deduction would be required by ADA or by other civil rights laws or building codes anyway. The best tax incentives are those that encourage desirable voluntary actions. This provision no longer does.

Where the barrier removal deduction would be useful today is in the area of communications and information technology. When the economy rebounds, many firms will likely invest in upgraded computer and telecommunications systems. Unlike architectural barriers, however, the law does not provide a comparable tax deduction for removing communications barriers. Since the law also does not generally require firms to use accessible information technology, a tax deduction here would be especially valuable as an incentive to voluntary measures.

Therefore, NCD recommends that Congress amend the barrier-removal deduction to include the major new barriers that people with disabilities face today such as information-access and communications technology barriers. Workable guidelines for Web access are available from the

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[94]GAO, Note 71, supra.

[95]26 USC Sec. 190.

Web Accessibility Guidelines of the World Wide Web Consortium[96] and, for a variety of pertinent hardware and software, from the federal procurement regulations implementing Section 508 of the Rehabilitation Act of 1998.[97]

As a second example, the disabled access credit gives small businesses a 50 percent tax credit up to a maximum of $10,000 per year of "eligible access expenditures."[98] Although acquisition or modification of equipment is an important category of eligible access expenditures, the IRS's interpretation of the law has been especially restrictive and harmful in this area, making it all but impossible for businesses to prove that access was the motive for the purchase.[99] NCD recommends that as part of any economic growth package including tax code changes, Congress revise the disabled access credit by providing clear standards by which the voluntary accessible-design efforts undertaken by small businesses on behalf of employees and customers can be suitably encouraged.

4. SECTION 508

The most far-reaching accessible design program in our nation has now been in operation for a year and a half. Section 508 of the Rehabilitation Act requires federal agencies in their procurement of electronic and information technology (E&IT) to purchase goods and services accessible to persons with disabilities, except where certain exceptions such as unavailability or

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[96]http://www.w3.org

[97]48 CFR Parts 2, 7, 10–12 and 39.

[98]26 USC Sec. 44.

[99]A number of restrictive interpretations of the provision have been issued in private letter rulings that have no precedent value but that do reflect IRS thinking. In the aggregate, these suggest that intention to accommodate individuals with disabilities is not sufficient to trigger the credit, and that with respect to employment the credit is not available to firms with fewer than 15 employees, since such firms are not covered by Title I of ADA.

technological impossibility or undue burden apply.[100] Thus far, neither the apocalyptic fears of many of its detractors nor the utopian hopes of some of its supporters have been realized. The world has gone on, substantially unchanged.

(a) EARLY RETURNS

The year 2002 has continued to witness the growth and refinement of useful resources, particularly information resources needed by government procurement officials, E&IT vendors and citizens with disabilities to better understand their rights, responsibilities and opportunities under the law. Such efforts as the General Services Administration (GSA)-sponsored Federal Information Technology Accessibility Initiative have produced and maintained the Web portal www.section508.gov, and information about accessible products and lists of federal agency Section 508 contact designees plus other valuable information are forthcoming through that site. At the same time, the GSA-sponsored Accessibility Forum has strengthened the partnership between the Federal Government, industry and consumer groups in coming to consensus under the new law.[101] In addition, a number of other federally supported resources have been developed to provide relevant information and technical assistance to other key sectors such as the education system and state governments.

But while awareness of, information about and access to resources necessary for complying with Section 508 have all increased, several other developments give cause for concern. On the last day of 2002, notice was published of the government's intent to make an important change in the Federal Acquisition Regulation governing the timetable for implementation of the law. Micropurchases (small purchases made in essence on government credit cards by various

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[100]PL 105-220, Section 408(b), codified at 29 USC Sec. 794d.

[101]See, generally, Accessibility Forum Web site (http://www.accessibilityforum.org).

employees outside the formal federal procurement structure) had been exempt from most 508 requirements through 2002. That deadline has now been extended by almost another two years.[102]

Though the proportion of E&IT procured through micropurchasing is not large, the significance of the extension lies in the reasons given for it. One stated reason was the failure of manufacturers to provide sufficient package information or other data to allow micropurchasers to assess the accessibility of various items. While this failure surely does not represent a deliberate effort by any sector of industry to undermine full implementation of the law, the delay does highlight the vulnerability of the 508 process. This situation suggests that where industry for whatever reason has failed to take the lead in implementing a 508 goal or requirement, the government has been without practical means for achieving compliance. In a business environment where desire to innovate may be tempered by harsh cost considerations, and where nonmilitary government purchasing is likely to grow at a far slower rate than in recent years, concern is warranted whether the momentum toward compliance with both the letter and spirit of 508 can be maintained.

A related problem is the unevenness of Section 508 monitoring. As discussed in detail in last year's report, the law does not contain provisions for ongoing monitoring of many key practices, such as the number of instances in which agencies use the "undue burden" or other defenses, the alternative methods agencies are using to provide required access to their employees or the public when E&IT cannot be made accessible, or even the ways procurement officers are weighting accessibility in comparison with other legal requirements in evaluating competitive bids.

While GSA appears to have a good general sense of what is going on in the proverbial trenches, we believe a more robust involvement on the part of DOJ would also be very helpful. NCD recommends that DOJ, in fulfilling its reporting requirements to the President and Congress under the law, expand its assessment to include not only the accessibility of federal agency Web

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[102] 67 Fed. Reg. 80321 (December 31, 2002).

sites (as it has surveyed in the past), but also the degree to which agencies have met other expectations and resolved persisting issues. DOJ's next report is due this year. Also, this year's reauthorization of the Rehabilitation Act raises the possibility that Section 508 could be amended. This convergence creates a great need for DOJ to put all relevant information before Congress and the public.

In addition, a number of key interpretive issues remain that must be authoritatively resolved if federal procurement officers are to have the guidance and clarity they need to apply the law consistently and soundly. Together with industry and the public, they need to know the answer to such questions as how to define "undue burden" in relation to a governmental payer. This in turn squarely raises the question, more pressing than ever in the current fiscal and economic climate, of how the development costs of accessibility should be allocated between industry producers and governmental purchasers.

As a component of WIA, the Rehabilitation Act, including Section 508, is up for reauthorization this year. Congress will thus have an opportunity to review 508 fully. NCD hopes that Congress and the Administration will remain faithful to the starkly simple goal of equality and to the enormous potential of technology that combined to bring Section 508 into being.

(b) NEW LAWS

Two important new statutes enacted in 2002 may have significant implications for Section 508. The first of these, the Electronic Government Act of 2002 (E-Government Act),[103] appears to strongly support Section 508 principles. Indeed, the concepts of greater governmental communication with the citizenry through electronic means that underlie both the E-Government Act and Section 508 are very similar.

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[103]The E-Government Act, Note 67, supra, at Sec. 3602 (f)(13).

The E-Government Act signals a new level of centralization and standardization in the management of governmental information resources. From the design of Web sites to the informational content of Web pages, federal E&IT practices are likely to come more and more under the management of the OMB's new chief information officer. This consolidation offers potentially valuable support for achieving 508 goals, but much will depend on the philosophy underlying the OMB's overall approach to e-government. This matter will be discussed further in section 6 of this chapter.

Here the equally profound implications of another major statute must also be taken into account. The Homeland Security Act will draw over 20 federal agencies together under a unified administrative umbrella for a purpose that necessarily subordinates open and expansive communication with the public to pressing national security imperatives. The issues posed by the new department for Americans with disabilities will be discussed at greater length in Chapter 13, but one key concern regarding Section 508 must be expressed here. Bearing in mind that 508 contains exceptions to accessibility requirements for technology used in national security systems,[104] NCD trusts that the new department will not interpret this exception in ways that inadvertently undermine the applicability of Section 508 to the vast bulk of its personnel, public contacts and ongoing activities.

(c) THE CONGRESSIONAL ACCOUNTABILITY ACT

Owing to the separation of powers doctrine under the Constitution, Congress is not automatically covered by many of the laws administered by the executive branch. This includes civil rights laws such as ADA. In 1995, Congress enacted the Congressional Accountability Act (CAA)[105] that applied a number of major laws to Congress itself and set up mechanisms for their administration.

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[104]29 USC Sec. 794d (a)(5).

[105]2 USC Sec. 1302.

Congress is still not subject to the requirements of Section 508; nor are such "Congressional instrumentalities" as the Library of Congress, the Government Printing Office or the GAO. In 2001, the Congressional Office of Compliance (which administers the CAA) recommended that Congress bring itself under the provisions of Section 508.[106] Although we are not aware of any opposition within Congress to this recommendation, or any serious dispute with the reasoning of the Office's recommendation, no action has thus far been taken.

NCD commends the Congressional Office of Compliance for describing its efforts, to date, to address the exclusion of the U.S. Congress from coverage under Section 508. (See http://www.compliance.gov/reports-studies/ada_12-02/ada_report.pdf, pages 16-17.) In its report, the Board of Directors of the Office of Compliance has recommended that Congress amend the CAA to incorporate the substantive public access and employee access requirements of Section 508 of the Rehabilitation Act. See Interim Section 102(B) Report: Electronic Information Systems, Office of Compliance Board of Directors (November 13, 2001). The Library of Congress (as well as the Government Printing Office) has announced that it will voluntarily comply with Section 508's requirements. In addition, the House of Representatives has recommended that all offices and committees make their Web sites voluntarily 508-compliant; House Information Services is assisting offices in this effort. Moreover, the upgraded Senate Web site will be 508-compliant.

Believing that in this age of e-government no justification can exist for Congress not to embrace accessibility, NCD recommends that the108th Congress act without delay to enter the electronic age by immediately and comprehensively applying Section 508 to itself.

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[106]Interim Section 102 (but) Report: Electronic Information Systems Review and Report on the Applicability to the Legislative Branch of Section 508 of the Rehabilitation Act of 1973 as Amended (U.S. Cong., Office of Compliance, November 13, 2001).

5. THE FEDERAL COMMUNICATIONS COMMISSION

A number of issues falling within the jurisdiction of the Federal Communications Commission (FCC) have profound implications for opportunities available to Americans with disabilities in the information age. Taken together, they indicate that the FCC may have a greater influence on the destinies of Americans with disabilities than any other federal agency. It is important to note, however, that during the period covered by this report, the FCC has reconfigured one Consumer/Disability Advisory Committee to remove the term "Disability" from its title. NCD hopes that this does not translate into subordination by the new Consumer Advisory Committee of issues and matters of utmost concerns to individuals with disabilities.

(a) SECTION 255

i. THE MOVE TO BROADBAND

A year ago, NCD called upon the FCC to broaden its interpretation of the scope of Section 255 so that the law could ensure access to the emerging telecommunications services that people with disabilities, like other Americans, increasingly need in order to participate in education, the economy and mainstream society. A year later, NCD finds itself in the dramatically altered position of not merely asking for broadening of the law, but pleading with the FCC not to effectively wipe Section 255 out of existence.

In its responsibility to periodically re-evaluate its regulations, the FCC has under advisement the question of whether all broadband technology and communications should be classified as "information services" rather than as "telecommunications services."[107] While this may seem an abstruse technical question, the distinction is in fact critically important because only

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[107]FCC Press Release, In Re TELEPHONE-Based Broadband Internet Access Services, (February 14, 2002).

telecommunications services, not information services, are subject to the accessibility requirements of the law.[108]

Section 255 of the Telecommunications Act of 1996[109] requires that manufacturers of telecommunications and "customer premises" equipment (your desk phone, cell phone, etc.) and the providers of telecommunications services (your local and long-distance phone companies) make their equipment and services accessible to users with disabilities, to the extent readily achievable. What advocates and many members of Congress did not appreciate when this law was passed was that "telecommunications" services represented a rapidly shrinking and old-fashioned portion of the communication taking place via the telephone network. High-speed data, graphics, faxes, e-mail, cable and other communication modalities and services are steadily supplanting traditional one-to-one dial-up voice calls as the ways Americans telecommunicate. As a result, we now face a situation where only voice communication, and not data or pictures, and only the equipment or parts of equipment that facilitate voice communication over the phone are covered by Section 255. And increasingly, even this basic voice communication is being routed to broadband transmission. At a time when broadband is expanding its range of communication capabilities (e.g., to include video relay services for people who are deaf or hard of hearing), it is important to realize the increasing impact that FCC rulings or policy decisions will have.

If the Commission rules that all broadband is per se information services, then everything carried via broadband, including voice communication, will become immune from civil rights protection under Section 255. Hence, though still on the statute books, Section 255 will become more and more irrelevant as voice communication migrates to broadband.

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[108]47 USC Sec. 255 (b); also NCD letter to the FCC (August 6, 2002) (currently available at http://www.ncd.gov/newsroom/correspondence//fcc_08-06-02.html).

[109]PL 104-104 Sec. 255, codified at 47 USC Sec. 255. Also 36 CFR Part 1193.

While NCD does not presume to know where the line between traditional telecommunications and new information services should be drawn, we do know that Congress intended to protect access to the telephone system for people with disabilities. Accordingly, NCD urges the FCC not to confuse economic regulation with protection of civil rights. NCD recommends that the FCC promptly make clear its appreciation that neither periodic regulatory relief nor changes in telecommunications technology will be permitted to underline the protections afforded to people with disabilities under Section 255 of the Communications Act.

If the FCC could point to steady progress toward accessibility, its belief that civil rights enforcement was no longer necessary might be credible. But the Commission has offered no such evidence. Indeed so far as is known, the Commission has collected or analyzed no recent data concerning industry practices, consumer satisfaction with accessibility of various products and services, or any other matter that would justify the Commission's concluding that Section 255 need not be enforced.

To effectively define the statute out of existence in this informational vacuum would be all the more unjustified and insensitive. NCD recommends that regardless of its final determination respecting broadband, the FCC should immediately clarify that Section 255 protections are an issue of civil rights, not of deregulation, and as such, should not be interpreted in a way that deprives people with disabilities of the protections of the law.

ii. ENFORCEMENT

Preserving the protections of the law requires more than simply avoiding its obliteration. NCD therefore reiterates its request made to the Commission in last year's report and in our June 2001 Accessible Future report[110] to develop procedures for investigating Section 255 complaints; developing appropriate sanctions for those cases where manufacturers, vendors or service providers are found to be out of compliance; taking an active role in helping complainants to

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[110]The Accessible Future, Note 1, supra.

evaluate contentions by respondents of not being readily achievable; reinstituting the Market Monitoring Report or other procedures to evaluate industry progress in achieving accessibility; and identifying areas of research and development where more focused efforts, resources or investment may be required.

(b) THE E-RATE

Since its enactment as part of the Telecommunications Act of 1996, the e-rate has provided grants and subsidies worth billions of dollars to libraries and schools to access the Internet and other electronic information resources. These subsidies are targeted at institutions in economically disadvantaged areas, which might otherwise have few resources for keeping up with the information revolution. Although the e-rate program reflects our nation's historic commitment to telecommunications access for all, there is ground for concern that people with disabilities continue to be excluded from the benefits of this commitment. Simply put, the problem is that the FCC has failed to require e-rate grantees to utilize accessible equipment. For this reason, we fear that many people with disabilities are not benefitting from the e-rate subsidies targeted to their schools and libraries.

Pursuant to discussions between the FCC and NCD in 2000, generic notices were posted on the e-rate Web pages setting forth the accessibility expectations of the program. NCD expected this would be the first step in a series of procedures leading in an orderly fashion and a reasonable time to publication of rules and implementation of specific contractual requirements. However, as of this writing, the Commission has made no further moves in this direction.

Owing to complexities in the law, some observers have suggested that the FCC may not possess the authority to impose accessibility requirements on e-rate grantees. If the FCC likewise believes this to be true, NCD urges it to make this fact known so that advocates can begin the necessary work of obtaining either added legislative authority or the required cooperation of

other federal agencies. If on the other hand the FCC does regard itself as authorized to act upon the promise of accessibility here, we urge it to initiate the regulatory process without delay.

(c) CELL PHONE ACCESS FOR USERS OF HEARING AIDS

In last year's report NCD commended the FCC for issuing a Notice of Proposed Rulemaking (NPRM) designed to develop a record on whether wireless phones should be required to be hearing aid compatible.[111] The Hearing Aid Compatibility Act of 1988 had exempted such phones from that requirement but had also provided for periodic review by the FCC of the need to continue the exemption.

Based on advances in technology, NCD believes this exemption to compatibility requirements should be promptly eliminated. We anticipated that the record developed by the FCC under the NPRM would amply demonstrate that the technology exists and the need is great for such a step.

To our knowledge the FCC has not released any findings or entered any orders pursuant to this NPRM. NCD recommends that the FCC publish the findings of its cell phone hearing aid compatibility inquiry, and, if (as we expect) they support the technical feasibility of cell phone–hearing aid compatibility, to implement a timetable for its achievement. If the record does not support the potential for accessibility using currently extant technology, then we urge the FCC to develop a plan on an expedited basis for bringing together the key stakeholders to implement and monitor the necessary additional research and development.

Whatever the FCC's findings, silence and inaction are inexcusable. It is time for the FCC to face up to this issue and ensure that the telecommunications industry faces up to it as well.

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[111]Notice of Proposed Rulemaking, In Re Section 68.4 of the FCC's Rules Governing Hearing Aid-compatible Telephones (November 14, 2001); Compare FCC Wireless Telecommunications Bureau Order granting delays in compliance with deadlines for making wireless phones compatible with emergency 911 calling systems (June 2002) (currently available at http://www.fcc.gov/cgb/dro/headlines.html).

(d) AUDIO DESCRIPTION

Audio description or descriptive video (also known as video description) is to people who are blind what closed-captioning is to people who are deaf. Through insertion of narrative descriptions of the key visual events in the program, persons who are blind or visually impaired can follow what is going on.

The Telecommunications Act of 1996 instructed the FCC to conduct research into this process.[112] Based on the studies, the FCC adopted rules requiring large commercial and cable broadcasters to carry a minimum number of hours of video-described programming each quarter.[113] The requirement went into effect on April 1, 2002.

A number of major broadcasters, including the Public Broadcasting System and Turner Classic Movies, have been presenting video-described programming for some time, and a number of other broadcasters have either begun to do so or have indicated an interest in doing so, according to information reaching NCD. Nevertheless, others objected. In November 2002, in a suit filed by the Motion Picture Association of America, the U.S. Court of Appeals for the District of Columbia Circuit struck down the FCC's video-description rule, characterizing it as without statutory basis.[114]

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[112]47 USC Sec. 613 (f-g), as added by PL 104-104 Sec. 713 (f-go).

[113]In striking down the FCC rule, the court noted that descriptive video differs from closed captioning in requiring the creation of new program content in the form of narrative. Nevertheless, the decision does not appear predicated on any ground relating to abridgment of the First Amendment free speech rights of program producers. Rather it is based on a straightforward determination that the statute did not authorize the action taken by the Commission.

[114]*Motion Picture Association of America v. Federal Communications Commission*, F. 3d (D.C.ir. No. 01-1149, November 8, 2002) (currently available at http://www.ll.georgetown.edu/federal/judicial//dc/opinions/01opinions/01-1149a.html).

By the time this report is published, the deadline for appealing this decision will have passed. As of this writing NCD has no information on whether the FCC plans to appeal. If the current decision stands, NCD trusts that the Commission will quickly assess what administrative or legislative steps are necessary to reinstate or repair appropriate description requirements, and to build awareness in the involved industries of the importance and feasibility of this valuable resource.

In the Commission's further deliberations concerning video description, NCD encourages the FCC to approach the subject comprehensively and to assess means for providing this service on both entertainment and public affairs programming, including all emergency preparedness information.

6. E-GOVERNMENT

The E-Government Act of 2002 marks a watershed in the development and organization of federal information policy and in the role of the Federal Government on the Internet.[115] Among the Act's key provisions are authorization of a four-year fund to meet the costs of projects including those that develop interagency and even intergovernmental (federal, state and local) subject-matter-based Web sites; creation of a permanent office of e-government run by a presidentially appointed administrator in the OMB; and provisions calling for the development of common practices and policies governing the informational content of federal Web sites.

Also of importance, this new law contains several references to the accessibility of federal Web sites and to the requirement that activities undertaken pursuant to the act be consistent with the provisions of Section 508 of the Rehabilitation Act.[116]

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[115]44 USC Secs. 3602 (f)(5), 3604.

[116]44 USC Sec. 3602 (e)(6) and (f)(13).

Recognizing that the procedures adopted by the new office will play a large part in determining how effectively the law's commitment to accessibility is operationalized, NCD recommends that as soon as appointed, the administrator (the chief information officer [CIO]) clearly restate the office's commitment to accessibility and take steps to incorporate that commitment into all guidelines, procedures and expenditures. To assist the CIO, NCD is eager to work with the new office to ensure fullest awareness of the range of accessibility issues confronting users of federal electronic information resources; provide the administrator with early warning of new problems and prompt feedback on attempted solutions; and to ensure the most up-to-date information on accessibility strategies and resources.

The E-Government Act represents nothing less than the preference for electronic communication as the medium of exchange between citizens and government where possible. Few commitments could have more profound implications for the lives of Americans with disabilities.

If done right, e-government will be one of the greatest forces for inclusion and empowerment in our history. If e-government is done wrong, Americans with disabilities may be condemned for generations to inequality, isolation and despair. For their sakes as individuals and for the sake of our society that so greatly needs their diverse skills and energies, we must make sure it is done right.

International Issues

Events of the past two tragic and tumultuous years have made more clear than ever that what happens in other countries profoundly affects the United States, and what we do has a great impact on the people of other nations. This interconnectedness is equally true for disability policy as practiced at home and as advocated abroad.

NCD will be releasing a major report on disability rights and foreign policy. Pending this important study, a few issues should be noted here.

1. HUMAN RIGHTS

The scope of our interests, impact of our laws and strength of our economic institutions inevitably influence domestic policies of other countries in a variety of ways. But in the area of disability policy, perhaps as much as in any other sphere, respect for America's efforts and achievements principally explains our impact on others. Laws such as ADA have served as models for civil rights legislation in other countries, and our grassroots advocacy strategies have been emulated in many lands.

Without imposing our will on other societies, our government can do many things in its official relations with other nations to encourage practices that respect the dignity and equality of people with disabilities. Some of these potential measures may be matters of discretion, others matters of law.

At a minimum, our responsibilities and opportunities in these areas include four key elements. First, our sensitivity to human rights violations in other nations, which has led to the denunciation of discrimination and mistreatment of racial and ethnic minorities, religious worshipers and women, must include equal condemnation and spotlighting of serious discrimination or oppression of people based on disabilities.

Second, U.S. foreign aid, bilateral and multilateral development programs should back up this commitment with requirements for inclusion of people with disabilities on terms of equality with other identifiable groups. Measures to bring about these results would include involvement of people with disabilities in decisionmaking processes that bear on their interests, and their inclusion in all efforts to achieve diversity in management of development programs.

The third key element in a policy of inclusion is that people with disabilities should be involved in the United States' prioritization and funding of development projects. For many years the NCD and the State Department have enjoyed a close collaborative relationship, and individuals with disabilities have been involved in planning some of our foreign assistance and international development efforts.[117] Through continuation and expansion of these relationships, the requisite representation can be ensured and the required expertise located and developed.

The fourth element of this strategy involves participation by persons with disabilities in private, nonprofit organizations and nongovernmental organizations engaged in such endeavors as cultural exchanges and provision of technical assistance to developing nations.

In this connection, NCD commends the State Department for supporting internship programs that allow persons with disabilities to serve with organizations pursuing international cooperation and development goals. Such internships should contribute to making these organizations more sensitive to the issues facing people with disabilities as employees, partners or recipients of services and aid.

Underlying these goals are the legal requirements that may apply. These issues will be examined in detail in NCD's upcoming report. It is enough to say for the moment that important provisions of such key statutes as the Foreign Assistance Act are subject to Section 504, and as such that a variety of programs operating in the international arena are obliged to comply with important

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[117] e.g., NCD Letter to the Hon. Colin Powell (July 18, 2002) (currently available at http://www.ncd.gov/newsroom/correspondence/powell_07-18-02.html).

nondiscrimination requirements. Similarly, in order to avoid discriminating against either potential employees with disabilities or others having business with them, American embassies and potentially other consular facilities cannot be operated without regard to their accessibility.

2. INTERNATIONAL AGREEMENTS AND TREATIES

(a) UN CONVENTION

Efforts are under way to adopt a UN Convention on the rights of persons with disabilities. The time is long overdue for these citizens of every nation to be recognized and protected under binding international conventions, in the same way the rights and needs of ethnic and religious minorities, children and women have been recognized and affirmed.

NCD has been active in explaining the significance of the proposed Convention[118] and expects to continue its involvement in providing briefings and updates during 2003. NCD recommends that the U.S. government declare its support for and its intention to become a signatory of the draft convention, and that the United States enter actively into such negotiations and discussions as may be required to finalize an acceptable document.

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[118]White Paper: Understanding the Role of an International Convention on the Human Rights of People with Disabilities, An Analysis of the Legal, Social and Practical Implications for Policy Makers and Disability and Human Rights Advocates in the United States (NCD 2002) (currently available at http://www.ncd.gov/publications/unwhitepaper_05-23-02.html).

(b) OTHER INTERNATIONAL AGENCIES AND COVENANTS

NCD is pleased to note that the World Bank has appointed a consultant on disability. As international financing agencies such as the World Bank and International Monetary Fund broaden their focus to take environmental and human rights implications of their projects into account, they should develop procedures for ensuring that issues relating to people with disabilities are included in these considerations. To facilitate this process, the United States should encourage these organizations to incorporate disability impact into any formal impact reviews they conduct.

Likewise, as international conventions come up for renewal and amendment, ranging from those governing civil aviation to those covering postal and telecommunications practices, the U.S. delegations should include persons with knowledge about the implications of these conventions for persons with disabilities. At first glance, some might suppose such implications would be small or that most treaties would have no disability-specific implications or provisions. This is not necessarily true. For example, the capacity of nonprofit organizations in this country to ship AT or other materials and supplies to disability organizations in developing countries is influenced by postal regulations bearing upon the cost of such shipments.

Major new issues are also emerging within the evolving structures of world trade. If a nation subsidizes development and deployment of AT, does such assistance constitute an impermissible trade subsidy to domestic producers? Likewise, do accessibility design requirements unfairly restrict trade opportunities if, in order to meet the standards of one market country, the product is made too costly to be competitive in another?

Beyond the answers to specific questions such as these, more fundamental questions must be addressed including what procedures the Office of the U.S. Trade Representative, Department of Commerce and other entities will utilize for identifying disability-related trade issues, or for deciding what our negotiation posture on such issues should be. Without consultation and

outreach to appropriate sectors of the disability community, the existence of these questions, let alone the best means for resolving them, may never be known, and countless opportunities for improving the effectiveness of laws, programs and expenditures will be lost.

To deal with these issues systematically, NCD recommends that the Office of the U.S. Trade Representative establish procedures for assessing the disability policy implications of all trade agreements and negotiations. Trade policy can be an effective and potentially profitable tool for encouraging development and use of assistive and accessible technology around the world, provided that trade policy and negotiations are informed with knowledge and awareness of the issues and possibilities.

Homeland Security

1. COMMUNITY RESPONSE

In last year's annual report to the President and Congress, NCD emphasized that homeland security, domestic preparedness, emergency planning and other aspects of our nation's response to tragedy and terror needed to be carried out with all Americans in mind. Giving several examples of measures that had been or might be designed in ways that would inadvertently leave people with disabilities unprotected, we urged that no program could be fully realized if it did not strive to protect all Americans.

A year later, results are mixed. Transportation security measures have taken Americans with disabilities into account, but a number of evacuation, preparedness and other plans have failed to carry these principles into effect. For example, some of the issues involved in evacuation planning of large buildings where substantial numbers of people with disabilities might be located were encountered by the U.S. Access Board (which dealt with them by involving its staff in the evacuation-planning process). While not purporting to be comprehensive, the Board's discussion of how it met and overcame these issues is instructive for anyone responsible for making similar plans.[119] The process encompassed matters ranging from technology that can be useful in evacuations, to assembly points, to looking for people, to the necessity of involving the building's occupants themselves in the planning process; all of these must figure into effective planning on any large scale.

Our nation is about to begin a large-scale smallpox vaccination program for health-care workers who would be called upon as our first line of defense if this terrible biological warfare agent were ever unleashed. Other vaccination campaigns as well as drug distribution programs, such as those that dispense medication to ward off thyroid damage in the event of a nuclear accident or

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[119]Access Currents, Vol. 8, No. 1 (January–February 2002) (available through the Access Board's Web site at http://www.access-board.gov).

sabotage, are likely to follow. But will critical information such as who should be vaccinated or what behavior or contacts should be avoided after drug administration be fully available to persons with disabilities who cannot read standard warning labels or package inserts, or who cannot hear instructions delivered in large-group settings? We do not claim to know how many Americans might be left at increased risk as a result of such information inaccessibility, but we do know that these issues must be addressed and cannot be left to chance.

Responsibility for incorporating these protections for people with disabilities is as widespread and dispersed as responsibility for the basic protective measures themselves. Federal, state and local government along with a host of private-sector partners are involved. The Federal Government must take the lead in ensuring that whatever is done by law or supported with federal funds meets all existing legal standards for physical, informational and program access. NCD therefore recommends that the HSD clarify the applicability of physical and program access, effective communication and other civil rights principles to all activities carried out or financially supported by it that bear upon the general public.

2. THE DEPARTMENT OF HOMELAND SECURITY

Establishment of the HSD during 2003 has been described by some as the largest restructuring of the Federal Government since creation of our current national security apparatus after World War II. One of the most daunting tasks facing the new department is amalgamation of almost two dozen federal agencies, each with its own history, traditions and cultures, into a single federal agency, developing priorities and uniform practices in areas where each has previously had its own way of doing things.

Such variation will also characterize the approach each takes to civil rights enforcement. As NCD's ADA report has shown,[120] interpretation and application of even a single civil rights statute such as ADA varies enormously among federal agencies, sometimes even among units of

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[120]ADA civil rights monitoring report, Note 1, supra.

the same department. Therefore, one of the new department's key responsibilities will be to establish a coherent and unified approach to civil rights enforcement over a range of statutes, and in connection with a broad variety of employment, procurement, contracting and enforcement practices.

Defining and establishing this new consensus will not be easy. Moreover, with all the management issues competing for the attention of the new department's leadership, civil rights could all too easily slip to a back burner. Likewise, because there will be understandable pressures to classify many projects and documents, the department must work hard to foster the realization that security and civil rights are not inconsistent or in conflict.

Not all the ways in which security and disability civil rights will need to be reconciled can yet be anticipated. Some obvious issues include implications of heightened computer security for users of screen readers or other access software, implications of teletype (TTY) use for secure phone lines and encryption, accessibility requirements applicable to specialized facilities or locations, implications of restricted access for people who utilize personal assistance services, and the recruitment and vetting of qualified personnel to provide AT and facility-access resources in departmental settings or for homeland security contractors.

NCD stands ready to assist the new HSD with these and other matters of mutual concern that may arise, and NCD hopes to establish a high-level relationship with the department at the earliest practicable time to develop the communication channels that will be needed to address both foreseen and unforeseen issues in the formative months and years of the HSD.

In order to ensure that civil rights issues receive the attention they need in the crucial formative days of new HSD systems and cultures, NCD recommends that the HSD designate a high-level official to act as liaison with NCD and with other federal agencies in relation to civil rights matters, and that the new department designate contact persons with department-wide authority

for each of the major disability civil rights statutes of concern to citizens, employees or contractors with disabilities.

Recommendations

List of Recommendations Contained in NCD 2002 Progress Report

Chapter 1

NCD recommends that the President's NFI should make improvement of data collection a high priority.

NCD recommends that these entities (ISDS and ICDR) seek input from the disability community regarding their most pressing concerns. NCD also recommends the new International Classification of Function be evaluated for its applicability to laws and programs in the United States and for its potential impact on the disability research agenda.

NCD recommends that in prioritizing disability research the Administration also fundamentally assess current research agendas to make sure that the potential benefits of a wide variety of environmental and community-design strategies can be fully taken into account in the formulation of public policy, and to ensure that suitable methodologies for gathering such information are developed and validated.

NCD recommends that research into these costs of living with a disability should likewise be made part of the national agenda, with a view both to documenting their nature and extent and to determining whether out-of-pocket costs of disability (such as the need for various forms of personal assistance) could be reduced by changes in the design of products, environments or communities.

NCD recommends the CBO undertake a review of these issues, including the extent to which it can seek input directly from individuals with disabilities on issues of concern to their lives, the extent to which nonfiscal impacts can be captured by existing scoring assumptions and

methodologies, the feasibility of rescoring selected existing programs where appropriate, and the capacity of current techniques to reliably take longer-term forecasts and extrapolations and cross-agency budgetary relationships into account.

Chapter 2

NCD recommends that the Administration recommit itself to the appropriate use of civil rights enforcement as one technique among those it will use to bring our commitment to equality to fruition.

NCD recommends that the OMB clarify its views regarding the applicability of pre-adoption regulatory-burden analyses to civil rights legislation, and to make clear that the defenses available to private entities under ADA should in most circumstances provide ample protection against excessive or burdensome demands.

NCD recommends that Congress adopt legislation extending federal hate crimes protection to a number of groups, including persons with disabilities.

NCD recommends that the new Congress recognize the growing importance of this issue and act to curb the discriminatory use of genetic information in insurance and employment, while there is still time.

NCD recommends that the Administration undertake research during and after the 2004 election campaign aimed at determining whether or not significant numbers of voters with disabilities who might not otherwise have been able to vote were facilitated in doing so by the law, and whether or not significant numbers of persons with disabilities who could not previously do so were enabled to exercise the right of a secret ballot.

NCD recommends that DOJ publicly affirm its commitment to the principles and the use of Section 504 as an important instrument for ensuring full access and civil rights for all citizens. In this connection, we also recommend that the Administration revitalize and empower the Interagency Disability Coordinating Council as a major vehicle for the coordination of Section 504 policy and implementation among the numerous federal agencies that must be engaged if the law is to achieve its full potential.

Chapter 3

NCD recommends that the Department of Education update its policy guidance on the relationship between special education and performance testing.

While bearing in mind the need to review and modernize all programs, NCD recommends that in reauthorizing IDEA Congress remember the accomplishments and achievements attributable to this law.

NCD recommends that Congress provide authority and resources for effectively monitoring all aspects of the revised IDEA over the coming years.

NCD recommends that in its review of the National Commission on Special Education's report Congress seek testimony from parents and students who have been obliged to utilize due process in order to overcome low educational expectations, and who have benefitted from the services and outcomes their determination brought about.

NCD recommends that Congress should consider the scope and availability of resources that will be necessary to effectively impact the high-incidence diagnosis problems cited by the Commission. In considering this issue Congress must also bear in mind that correction of the culturally diverse over-representation problem, and indeed reduction in the overall rate of increase in the number of students found eligible for special education services, will also depend

in large part on the ability of teachers and schools to provide adequate educational and related services.

Without attenuating the responsibility of the public school system to provide special education services to all students found eligible for them, NCD recommends that Congress look for means by which the relative roles of educational and budgetary considerations in school system decisionmaking about individual children can be more clearly separated and differentiated than has hitherto been the case.

NCD recommends that Congress incorporate into IDEA strong antidiscrimination provisions aimed at ensuring that charter and other choice schools receiving funds, whether directly or indirectly, under NCLB or other federal programs be reciprocally required to provide the identical services and accessibility to students with disabilities that public schools would be required to provide.

NCD recommends that Congress take steps to ensure that accountability extends to the use of and the assessment of students for AT.

NCD recommends that IDEA make clear that the same requirements as apply to physical access to school facilities are also applicable to program participation including access to E&IT resources and educational media included in the mainstream curriculum.

NCD recommends that the Department of Education take steps to implement regulations making mandatory such textbook accessibility standards as its current voluntary consensus-building effort yields, and if its efforts result in no such consensus that the department nevertheless adopt suitable regulations by no later than the end of 2003, based on the findings made and the best practices discovered during the next year.

Chapter 4

NCD recommends that the congressional statement of findings underlying any prescription drug legislation include detailed demographic information on the number of persons with disabilities included in the age, beneficiary or other categories of persons covered by the new law, and the number likely to be included as time goes on.

NCD recommends that if economic eligibility standards are used to determine eligibility for any benefits, Congress take notice of all available data concerning the income of Medicare recipients with disabilities under the age of 65, whose average incomes are likely to be lower than those of the Medicare-recipient population as a whole.

NCD recommends that any prescription drug plan provide assurances that otherwise eligible people with disabilities who decline for specified reasons to join the plan will still be entitled to obtain the drug benefits available under the new program.

NCD recommends that CMS proceed with its prior undertaking and establish a timely and transparent process for identifying and reviewing the efficacy of all existing national coverage decisions, with a view to modifying or repealing those that cannot be justified in the light of current medical thinking or law.

NCD recommends that Congress urgently and immediately hold hearings to examine the impact of state Medicaid cuts on the lives of people with disabilities, including hearings that assess the number of people likely to be forced into institutions as a result and the costs of such institutionalization to the program, and that Congress consider and adopt measures to prevent this needless tragedy and counterproductive fiscal result.

NCD recommends creation of a broadly diverse national commission to look into the issue of pain management and life preservation, with a view to comprehensively assessing not only the

medical, legal and ethical issues but also the support services and other complex needs and issues involved, and for the purpose of developing a national policy that will ensure that life with dignity, not death with dignity, commands our resources and attention.

NCD recommends that all FDA device review procedures be evaluated in terms of their impact on DME and other AT devices used by persons with disabilities. Beyond this, we recommend that CMS and FDA undertake a review of the legal issues surrounding the assessment and eligibility for insurance coverage of AT that may not fall within the jurisdiction of the FDA.

NCD recommends that DOJ issue an overview and update of the implementation of the America's Law Enforcement program to date, and consider means for involving people with mental illness and psychiatric treatment histories in the development and oversight of the program.

Chapter 5

NCD recommends that the OMB and the CBO begin developing cross-agency program scoring methods and unified budgeting models that will link the relevant activities and budget requests of various agencies so as to allow the impact of budget proposals on multi-agency policy initiatives such as *Olmstead* to be tracked and reported and so as to allow effective budgeting for multi-agency initiatives.

NCD recommends that Congress hold hearings and invite recommendations on coverage packages, including seller and purchaser incentives, that would help to meet the existing and foreseeable needs for greatly expanded private-sector participation in the financing of home and community-based services and care.

NCD recommends that the Administration conduct and publish a comprehensive audit of all state-based *Olmstead* implementation activities, designed to describe what has worked, to name

names of those states that have been successful or have at least tried as well as of those that have not, and to make certain that citizens and voters are as fully informed as possible about the values at stake in the responsiveness or unresponsiveness of their state officials and leaders.

Chapter 6

NCD recommends that with respect to transition or other major areas of overlap between the two statutes, Congress develop means to ensure coordination in the drafting and review of provisions and to ensure consistency between the language included in each reauthorization.

NCD recommends that discretionary grants be made on a trial basis to education-rehabilitation agency partnerships for transitional services, with success or failure and the availability of further funds to be contingent on the development and achievement of unified transition goals and without any opportunity for accountability being differentiated between them.

NCD recommends that the administration clarify its support for the NYLN and explore its fullest empowerment and most effective utilization.

NCD recommends that ODEP inquire systematically into the operation, integration and impact of the youth advisory councils, with a view to making suggestions for their continuance and improvement in the WIA reauthorization this year.

NCD recommends that Congress seek testimony from young workers to determine how their input into the operation of programs affecting them can be most usefully provided, and how such programs can be most effectively designed and implemented.

Chapter 7

NCD recommends that the SSA consult with its TWWIIA advisory panel, with the PABSS and BPA&O units of state P&A programs, with TWWIIA employment networks and with Social Security beneficiaries who have attempted to use the new law to determine whether or not its complexity has proven to be a barrier to effective utilization, and if so to identify technical assistance tools and regulatory or even statutory changes that might make the program more accessible and user-friendly.

NCD recommends that the Administration and Congress speedily address the question of whether or not Medicaid cuts are jeopardizing the success of work incentive provisions in TWWIIA aimed at preserving health insurance for Medicaid recipients who return to work, and if so to devise means for restoring the ability of the states to participate fully.

NCD recommends that the RSA and the SSA develop guidelines for dealing with requests for VR services from active ticket holders where the state VR agencies in question are operating under order-of-selection procedures that restrict the provision of the needed services.

NCD recommends that as part of the reauthorization Congress seek testimony on the extent to which state VR agencies obtain and utilize labor market information and labor-demand forecasts, and how such data are used in fashioning their services, outreach and programs.

Chapter 8

NCD recommends, however, that provision be made for an individualized assessment of each person or family, on the basis of which an appropriate time period for rehabilitation services should be determined.

NCD recommends that reauthorization require state welfare reform programs to enter into cooperative agreements with state VR agencies or other appropriate entities to ensure that the necessary screening, services and expertise needed to rehabilitate recipients with disabilities will be forthcoming.

NCD recommends that states be given authority to extend or waive the five-year limitations period for recipients with severe disabilities who cannot be placed owing to the unavailability of employment or of needed technology or transportation services.

NCD recommends that when people with disabilities are sanctioned or when they time out of eligibility, mechanisms for referral to the SSA be established.

Chapter 9

NCD recommends that the administration adopt with timetables a goal that the supply and variety of accessible housing for those who need it shall be proportionally equal to the overall housing supply for the population as a whole.

NCD recommends that HUD incorporate in its strategic plan baseline data, timetables and goals for home ownership by persons with disabilities comparable to the goals it has established for other definable population subgroups.

NCD recommends that HUD and DOJ jointly develop clear guidelines for determining what discrimination cases, other than those involving criminal conduct, will be referred to DOJ for further action, and indicating the policies DOJ will follow in litigating and disposing of such cases.

NCD recommends that FHEO should be elevated to a position reporting directly to the Secretary of HUD, possibly as part of the general counsel's office, and other steps should be taken to demonstrate and sustain an ongoing commitment to civil rights at the highest executive levels.

NCD recommends that a high-level national commission should be appointed by the President and Congress to study America's housing needs over the next generation and to make detailed recommendations for how they can be met.

Chapter 10

NCD recommends that DOT clarify the responsibilities of carriers, airport managers and contractual airport service providers for providing various forms of assistance to passengers with disabilities during the embarkation and disembarkation phases of their trips.

NCD recommends that DOT and DOJ address the accessibility issues posed by airport ticket machines and by other new customer-service technology.

NCD recommends that in the reauthorization of TEA-21, Congress require the involvement of state and local transportation agencies in *Olmstead* planning processes.

NCD recommends that the statutory criteria for paratransit eligibility be designed with a view to requiring local transit agencies to utilize standards established by state and local *Olmstead* plans in determining eligibility for service.

NCD recommends that the new law should include requirements and funding authorization for continued research in all the subjects noted in this section—for pilot and demonstration projects in various environments around the country, and for evaluating and disseminating results—and provisions for incorporating the most successful technologies and strategies into our overall transportation infrastructure.

NCD recommends that DOT comprehensively review this practice to make certain that conditional eligibility does not undermine the rights to paratransit services established under federal law.

Chapter 11

NCD recommends that Congress and the Administration establish a national commission to study not the already-known barriers to AT utilization, but instead the potential impact on existing programs, on people with disabilities and on government expenditure that can reasonably be expected to result through systematic and intensive application of technology.

NCD recommends that the AT Act be reauthorized.

NCD recommends that Congress amend the barrier-removal deduction to include the major new barriers that people with disabilities face today such as information-access and communications technology barriers.

NCD recommends that DOJ, in fulfilling its reporting requirements to the President and Congress under Section 508, expand its assessment to include not only the accessibility of federal agency Web sites but also the degree to which agencies have met other expectations and resolved persisting issues.

NCD recommends that the 108th Congress act without delay to enter the electronic age by applying Section 508 to itself.

NCD recommends that regardless of its final determination respecting broadband, the FCC should immediately clarify that Section 255 protections are an issue of civil rights, not of deregulation, and as such should not be interpreted in a way that deprives people with disabilities of the protections of the law.

NCD recommends that the FCC publish the findings of its cell phone–hearing aid compatibility inquiry and, if they support the technical feasibility of cell phone–hearing aid compatibility, to implement a timetable for its achievement.

NCD recommends that as soon as appointed, the administrator (the chief information officer of the OMB) clearly restate the office's commitment to accessibility and take steps to incorporate that commitment into all guidelines, procedures and expenditures under the E-Government Act.

Chapter 12

NCD recommends that the U.S. government declare its support for and its intention to become a signatory of the draft convention, and that the U.S. enter actively into such negotiations and discussions as may be required to finalize an acceptable document.

NCD recommends that the Office of the U.S. Trade Representative establish procedures for assessing the disability policy implications of all trade agreements and negotiations.

Chapter 13

NCD recommends that the HSD clarify the applicability of physical and program access, effective communication and other civil rights principles to all activities carried out or financially supported by it that bear upon the general public.

NCD recommends that the HSD designate a high-level official to act as liaison with NCD and with other federal agencies in relation to civil rights matters, and that the new department designate contact persons with department-wide authority for each of the major disability civil rights statutes of concern to citizens, employees or contractors with disabilities.

PART II

Major Activities Summary FY 2002

The National Council on Disability (NCD) continues to be a leader in the development and analysis of disability civil rights policies that affect 54 million Americans with disabilities and their families. With a budget authorization of $2,830,000, NCD conducted numerous activities in fiscal year (FY) 2002. Those activities highlighted policies, programs, practices and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability, from all cultural backgrounds. They also helped people with disabilities realize the promise of the Americans with Disabilities Act (ADA) by empowering them to achieve economic self-sufficiency, independent living, inclusion and integration into all aspects of society.

In FY 2002, NCD continued to review and evaluate new and emerging policy issues that impact people with disabilities. NCD continued to identify the overall needs and concerns of people with disabilities by conducting hearings, forums and conferences throughout the country, and by responding to thousands of telephone, e-mail and written inquiries on ADA and other disability civil rights issues.

NCD also continued its Disability Civil Rights Monitoring Project by releasing research and comprehensive reviews of the first 12 years of enforcement efforts under the 1988 Fair Housing Amendments Act and related legislation and of the first 27 years of enforcement efforts under Section 504 of the Rehabilitation Act of 1973, as amended.

The Disability Civil Rights Monitoring Project or Unequal Protection Under Law series grew out of NCD's 1996 national policy summit, where more than 300 disability community leaders from diverse backgrounds called upon NCD to work with federal agencies to develop strategies for greater enforcement of existing disability civil rights laws. On March 18, 1999, NCD produced its first report, *Enforcing the Civil Rights of Air Travelers with Disabilities*. The second report, *Back to School on Civil Rights*, on the enforcement of the Individuals with Disabilities Education

Act, was issued on January 25, 2000. The third report, *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act*, was released on June 27, 2000. The fourth report, *The Accessible Future*, was issued on June 21, 2001. The fifth report, *Reconstructing Fair Housing*, was released on November 6, 2001. The enforcement reports to follow in this series will be on Section 504 of the Rehabilitation Act and the Civil Rights of Institutionalized Persons Act.

Major activities for FY 2002 also included the release of *Understanding the Role of an International Convention on the Human Rights of People with Disabilities*, *Supreme Court Decisions Interpreting the Americans with Disabilities Act*, *Position Paper on Genetic Discrimination Legislation*, *Principles for Genetic Discrimination Legislation*, and *Brief Amicus Curiae of the National Council on Disability in Support of Respondents, Chevron U.S.A. Inc. v. Mario Echazabal.*

In addition, six of President Bush's nominees to NCD were confirmed by the U.S. Senate: Lex Frieden, Houston, Texas; Robert R. Davila, Ph.D., Rochester, New York; Young Woo Kang, Ph.D., Munster, Indiana; Kathleen Martinez, Oakland, California; Carol Hughes Novak, Tampa, Florida; and Patricia Pound, Austin, Texas.

ACTIVITIES FOR FY 2002

NCD conducted a variety of activities in FY 2002 that significantly increased consumer input into public policy issues impacting people with disabilities and provided information on NCD's daily operations. A summary of those activities follows:

NCD Evaluates HUD's Enforcement of Fair Housing
November 6, 2001, Washington, DC

NCD conducted a news conference to highlight the release of its report on the U.S. Department of Housing and Urban Development's (HUD) fair housing enforcement at the National Press Club in Washington, DC.

The report, *Reconstructing Fair Housing* (http://www.ncd.gov/newsroom/publications/fairhousing.html), evaluates HUD's enforcement of the Fair Housing Amendments Act of 1988 and Section 504 of the Rehabilitation Act as they relate to housing for people with disabilities and HUD's overall record during the past 12 years in enforcing the civil rights of people with disabilities under these laws.

NCD found that despite legislation from1988 that mandated improving fair housing, fair housing enforcement remains an unfulfilled promise for Americans with disabilities.

The report states that

- The past 12 years of civil rights enforcement by HUD have left America, and in particular people with disabilities, needing more.
- In fiscal years 1999 and 2000, people with disabilities became the single largest group to file housing discrimination complaints.

- By the late 1990s, HUD's investigations of housing discrimination complaints took nearly five times as long as Congress had mandated.
- Inadequate funding hampered administrative enforcement of civil rights laws.

NCD Commends Office of Compliance

November 20, 2001, Washington, DC

NCD applauds the announcement by the Congressional Office of Compliance recommending that Section 508 of the Rehabilitation Act of 1973, which requires access to the Federal Government's electronic and information technology, be made applicable to all Congressional Accountability Act–covered employing offices on Capitol Hill, including the Government Printing Office, the Government Accounting Office and the Library of Congress.

NCD commends the Office of Compliance for their forward progress in advancing access to electronic and information technology to 54 million Americans with disabilities. This critical step is consistent with the advice and recommendation in NCD's June 14 report *National Disability Policy: A Progress Report* (http://www.ncd.gov/newsroom/publications/01publications.html) that urged Congress to take whatever steps are necessary to amend the Congressional Accountability Act so that the Government Printing Office does not remain exempt from federal accessibility laws and regulations, including Section 508, as they pertain to Web sites.

NCD encourages Congress to act promptly to incorporate these important recommendations from the Office of Compliance that will advance the civil rights of all people with disabilities.

The electronic information systems interim report from the Office of Compliance can be found at http://www.compliance.gov/.

NCD Publishes RFP

January 14, 2002, Washington, DC

NCD published a request for proposals (RFP) in Federal Business Opportunities seeking an independent contractor to conduct an inquiry and develop recommendations for consideration by Congress, the Administration and sovereign tribal governments to support community members who have disabilities in four interconnected areas: education, health, rehabilitation and independent living. The project should analyze the status of previous findings and recommendations and describe culturally competent best practices that contribute to improving the quality of life for American Indians and Alaska Natives with disabilities who live on tribal lands. The plan for this investigation should project a seven-month work schedule and involve a group of project advisers experienced in tribal community affairs. The approximate release and closing dates are January 30, 2002, and March 30, 2002, respectively.

NCD Files Supreme Court Brief

February 6, 2002, Washington, DC

NCD filed an *amicus* brief on February 1 with the U.S. Supreme Court in *Chevron U.S.A. v. Echazabal* (No. 00-1406), a case involving the Americans with Disabilities Act (ADA).

Echazabal is a major case in the Supreme Court's recent line of ADA cases examining the employment rights of people with disabilities. The Court will decide whether or not an employer may reject a job applicant with a disability who is qualified to do the job and not a safety risk to others in the workplace, but whose health condition may be speculatively worsened by the workplace environment. Oral argument is set for February 27, with a decision by the Court expected this spring.

NCD Continues Outreach to Limited English Proficient Populations

February 11, 2002, Washington, DC

NCD's policy of outreach to people with disabilities who are culturally diverse and limited English proficient (LEP) is long-standing. NCD began translating documents into foreign languages as early as 1995, five years before Executive Order 13166 on LEP went into effect. Most recently, NCD Web posted the Spanish and Vietnamese translations of the executive summary of *Reconstructing Fair Housing*. Both translations can be found at http://www.ncd.gov/newsroom/publications/01publications.html.

Additional translated documents include NCD's brochure (Spanish, Chinese, Tagalog, Korean, and Vietnamese); *The Accessible Future* (Spanish); *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation* (Spanish and Chinese); and *Back to School on Civil Rights* (Spanish).

NCD Participates in Congressional Disabilities Caucus

February 13, 2002, Washington, DC

NCD testified on the Individuals with Disabilities Education Act (IDEA) at the first Bipartisan Disabilities Caucus congressional briefing.

During the course of five studies on IDEA, from 1989 to 2000, NCD consistently learned that parents of children with disabilities are enthusiastic supporters of the law. They think it is a good law. Those studies include *Back to School on Civil Rights* (2000) (http://www.ncd.gov/newsroom/publications/backtoschool_1.html); *Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children Supplement* (1996) (http://www.ncd.gov/newsroom/publications/96school.html); *Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's*

Children (1995) (http://www.ncd.gov/newsroom/publications/95school.html); *Inclusionary Education for Students with Disabilities: Keeping the Promise* (1994) (http://www.ncd.gov/newsroom/publications/inclusion.html); *Serving the Nation's Students with Disabilities: Progress and Prospects* (1993) (http://www.ncd.gov/newsroom/publications/progress.html); and *The Education of Students with Disabilities: Where Do We Stand?* (1989) (http://www.ncd.gov/newsroom/publications/stand.html).

NCD presented to the Caucus its new working paper on IDEA reauthorization (http://www.ncd.gov/newsroom/reauthorizations/idea/idea.html).

IDEA is scheduled to be reauthorized by Congress in 2002. The IDEA statute is made up of four parts, including the Part A General Provisions section, the Part B Grants to States Program (including preschool grants), the Part C Infants and Toddlers program and the Part D Support Programs. Part B is permanently authorized. Congress must periodically review and reauthorize Parts C and D of IDEA (usually every five years) in order to ensure continuation of the activities included under these parts.

One of the nation's best tools in promoting education equity and excellence is a public education system that is focused directly on accountability, achievement and enforcement. To deal with the existing realities related to federal education policymaking, during IDEA reauthorization, NCD will use a variety of forums and mechanisms to solicit stakeholder input to advise the Administration and Congress regarding a range of critical policy issues. These policy issues and suggested policy options for reauthorization go to the heart of education reform for over six million students with disabilities and involve (a) accountability in federal education spending, (b) achievement and progress in the K–12 arena and (c) fidelity of implementation in all aspects of the IDEA entitlement program.

NCD Calls for Accountability for Students with Disabilities

February 27, 2002, Washington, DC

NCD called on funders, legislators and policymakers for accountability, achievement and fidelity of implementation for students with disabilities as the reauthorization of Individuals with Disabilities Education Act (IDEA) begins in Congress.

Congress crafted a statute in 1975 that, if faithfully implemented, will consistently produce quality outcomes for students with disabilities. Special education is statutorily defined as "specially designed instruction" that meets the "unique needs" of these students; each student's individualized education program (IEP) is to set forth his or her unique needs and individually designed instruction; and each student's placement is to be based on the IEP and be no more restrictive than necessary (20 USC 1402(25); 34 CFR 3000.552(a)(2)(b)). If IEPs are based on the unique needs of students, if instruction is individually designed, if IEPs are faithfully implemented and if the least restrictive environment requirements are followed, students will achieve quality outcomes while enjoying maximum interactions with their nondisabled peers. Compliance with the requirements of IDEA is a necessary condition for quality outcomes.

IDEA is now the most significant aspect of the federal involvement in public education for children and youth with disabilities. Rich or poor, urban, suburban or rural, all schools and districts are affected by special education. IDEA's basic premise is that all children with disabilities have a federally protected civil right to have available to them a free appropriate public education that meets their schooling and related service needs in the least restrictive environment, in regular classes, in the school the student would attend if not disabled. It is a law designed to work for every eligible student. Students with disabilities need the guarantee of consistency and high standards in their education.

President George W. Bush has recognized the importance of the role that a strong and effective IDEA plays in ensuring that no child gets left behind: the President has provided his immediate

and firm support of IDEA in his New Freedom Initiative (http://www.whitehouse.gov/news/freedominitiative/) and in his No Child Left Behind education proposal (http://www.ed.gov/inits/nclb/titlepage.html), which was passed by Congress in 2001.

NCD Releases Genetic Discrimination Legislation Paper

March 4, 2002, Washington, DC

NCD released a position paper (http://www.ncd.gov/whatsnew.html) calling for federal legislation providing strong antidiscrimination protection to people with genetic predispositions as well as those with already-manifested disabilities and health conditions.

For a number of years, NCD has recognized the harmful effects of discrimination based on individuals' genetic information and supported the need for federal legislation prohibiting genetic discrimination as well as the enforcement of existing legislation that may prohibit certain types of genetic discrimination. It has addressed the issue of genetic discrimination in several reports, including the following:

- ***Achieving Independence: The Challenge for the 21st Century*. July 26, 1996** (expressing serious concern about the quandaries and implications of obtaining and using genetic information; calling for further examination of the interface of genetic testing practices with antidiscrimination law and access to health insurance for people with disabilities).
- ***National Disability Policy: A Progress Report. July 26, 1996–Oct. 31, 1997*** (noting the potential for discrimination based on genetic information in employment, health care and other areas, and urging the President to work with Congress to enact legislation outlawing genetic discrimination and restricting access to genetic information by employers, insurance carriers and others).
- ***National Disability Policy: A Progress Report. Nov. 1999–Nov. 2000*** (applauding the Clinton Administration for issuing an executive order prohibiting certain types of genetic

discrimination by federal employers, and urging the prompt reintroduction of legislation prohibiting genetic discrimination by employers and health insurers).

- ***Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act.* June 27, 2000** (supporting the U.S. Equal Employment Opportunity Commission's position on genetic discrimination in its guidance on the definition of disability, which considered an individual discriminated against based on a genetic predisposition to disease or disability to be a person with a disability protected by the Americans with Disabilities Act (ADA) by virtue of being "regarded as" substantially limited in a major life activity; calling for technical assistance from federal agencies in emerging areas of ADA policy and enforcement such as genetic discrimination).

NCD's interest in genetic discrimination legislation stems partly from the fact that the need for this legislation arises due to narrow judicial interpretations of ADA, and these same interpretations also create the need for legislation to restore protections for individuals who have actually developed health conditions. NCD believes that the concerns of individuals with actual health conditions have not been fully addressed in the dialogue about legislative proposals to address genetic discrimination.

Genetic discrimination by employers and insurers has continued to be a systemic problem. NCD would agree that genetic information and genetic technology hold great promise for improving human health. However, the misuse of genetic information not only excludes qualified people from employment and without justification denies insurance coverage to people but also undercuts the fundamental purposes of genetic research.

NCD Releases Critical Analysis of Supreme Court Decisions on ADA

March 8, 2002, Washington, DC

NCD released *Supreme Court Decisions Interpreting the Americans with Disabilities Act* (http://www.ncd.gov/newsroom/publications/supremecourt_ada.html), a critical analysis of the Court's recent decisions involving the Americans with Disabilities Act (ADA).

In the past few years, the U.S. Supreme Court has issued a number of decisions that have dramatically changed the way ADA is interpreted; in most cases, contrary to what Congress intended. One decision in particular, *Board of Trustees of the University of Alabama v. Garrett*, 531 U.S. 356 (2001), devastatingly stripped the right of state workers to sue their employers for money damages for violations of Title I of ADA, which prohibits employment discrimination against people with disabilities. In response, NCD convened a series of meetings with disability policy experts to gain their assessment of the breadth and nature of the impact of Supreme Court decisions on ADA and other key civil rights laws.

This paper provides a summary of the Supreme Court's decisions through its 2000 term involving ADA and the significant implications of these decisions. It is intended to increase public awareness of ADA as interpreted by the Supreme Court and to give policymakers and ADA stakeholders an overview of ADA issues addressed by the Court, a synopsis of the decisions and the significant implications of each decision in helping or hindering the implementation of ADA. Finally, the paper is intended to assist in the examination of the work that remains to be done to realize the law's promise.

The Supreme Court will consider several ADA cases in its October Term 2001. The summaries of two of the cases decided to date are provided in Attachment A of the paper, which will be periodically updated to include information about new decisions and their implications. The Court's recent decision in *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, for example, took an inordinately restrictive view of what it takes to demonstrate a disability under ADA; thus

the paper's analysis of the implications of ADA cases should be read in light of these emerging decisions.

Disability is not the experience of a minority of Americans. Rather, it is an experience that will touch most Americans at some point during their lives. NCD is committed to tearing down the barriers to equality that face many Americans with disabilities. The Supreme Court's interpretations of this historic law have been largely inconsistent with the original intent of Congress and President George H. W. Bush in enacting the law and the desire of the American public. The Supreme Court must not be a roadblock in the promotion of policies that guarantee equal opportunity for all people with disabilities. People with disabilities must be afforded every opportunity to enter the mainstream of American life.

NCD Testifies before U.S. Senate on IDEA
March 21, 2002, Washington, DC

NCD testifies today on the Individuals with Disabilities Education Act (IDEA) before the U.S. Senate Committee on Health, Education, Labor and Pensions, presenting testimony on NCD's new working paper on IDEA reauthorization (http://www.ncd.gov/newsroom/reauthorizations/idea/idea.html).

NCD Conducts Summit on UN Convention
April 8, 2002, Washington, DC

NCD conducted a summit on the international convention on the rights of people with disabilities with 30 representatives from international human rights and national disability rights organizations. Human rights leaders who have worked to ban land mines and for the approval of UN conventions on the rights of children, women and indigenous people conferred with disability advocates on the content, strategies and process for developing an effective human rights convention for people with disabilities.

NCD Briefs Civil Rights Commission on IDEA

April 12, 2002, Washington, DC

NCD briefed the U.S. Commission on Civil Rights on the Individuals with Disabilities Education Act (IDEA), presenting NCD's new working paper on IDEA reauthorization (http://www.ncd.gov/newsroom/reauthorizations/idea/idea.html).

NCD Testifies before President's Special Education Commission

April 26, 2002, Washington, DC

NCD provided expert testimony to the President's Commission on Excellence in Special Education on the reauthorization of the Individuals with Disabilities Education Act (IDEA).

Specifically, NCD addressed what works and what can be improved at the U.S. Department of Education, Office of Special Education Programs (OSEP) so that educational outcomes for children with disabilities will be improved by the IDEA reauthorization.

NCD provided an in-depth analysis of OSEP's monitoring from the consumer perspectives contained in NCD's *Back to School on Civil Rights* report, as they relate to the reauthorization of IDEA.

NCD Provides Written Testimony to President's Special Education Commission

April 30, 2002, Washington, DC

NCD provided written expert testimony to the President's Commission on Excellence in Special Education Transition Task Force hearing on the reauthorization of the Individuals with Disabilities Education Act.

Specifically, NCD presented information on the status of transition, post-secondary education and employment outcomes for primarily 14- to 22-year-old youth and young adults with disabilities over the past 27 years. It also presented recommendations for national, state and local community action to improve those outcomes.

NCD Submits Testimony to Senate

April 30, 2002, Washington, DC

NCD provided written testimony for the record of the U.S. Senate Health, Education, Labor and Pensions Committee on discipline and the reauthorization of the Individuals with Disabilities Education Act.

The testimony included NCD's 1998 *Discipline of Students with Disabilities: A Position Statement* (http://www.ncd.gov/newsroom/publications/discipline.html), which is as relevant today as it was in 1998. It shares NCD's concern about the way this issue is being characterized and the potential harm to children with disabilities that may come from congressional efforts to revisit this issue.

NCD believes that instead of making it easier for schools to wash their hands of students with disabilities by giving schools new means to facilitate their discriminatory exclusion, policymakers must look for ways to address the needs of all students with and without disabilities so that they stay in school and succeed.

NCD Awards Research Contract

May 17, 2002, Washington, DC

NCD awarded a research contract to Kauffman and Associates of Spokane, Washington, to coordinate a seven-month project pertaining to people with disabilities on tribal lands with regard to education, health care, rehabilitation and independent living.

NCD Supports UN Convention

June 12, 2002, Washington, DC

NCD released its report (http://www.ncd.gov/newsroom/publications/unwhitepaper_05-23-02.html) supporting a United Nations Convention on the Rights of Persons with Disabilities (http://www.un.org/esa/socdev/enable/disA56168e1.htm). This worldwide, grassroots effort to develop international principles and provisions for people with disabilities seems ready to take action.

We are on the threshold of a new phase in the history of human rights worldwide. The conditions for a United Nations Convention on the rights of persons with disabilities are present and movement in that direction is building.

As NCD and the United States International Council on Disabilities convened a forum on a UN Convention, the Government of Mexico held a similar meeting in Mexico. The focus of many grassroots organizations is on protecting the rights and dignity of people with disabilities worldwide. The treaty-making process itself can raise general public awareness about the human rights of people with disabilities and highlight the abuses of those rights.

NCD states that

- The worldwide population of people with disabilities is approximately 600 million people;
- In both developed and developing countries, persons with disabilities face discrimination and are found disproportionately among the poorest segments of society.
- The fundamental rights of disabled persons—including the rights to education, parenthood, participation in elections, access to courts of law, and property rights—continue to be violated around the world.

NCD Presents Fair Housing Testimony

June 25, 2002, Washington, DC

NCD presented testimony to a joint hearing of two House Financial Services Subcommittees on discrimination against people with disabilities and people from culturally diverse communities in public housing. The hearing examined complaints that fair housing policies are inadequately enforced. Discrimination complaints against people with disabilities now surpass complaints based on race. Findings and recommendations from NCD's recent report, *Reconstructing Fair Housing*, were discussed throughout the hearing.

NCD Releases Recommendations on IDEA

July 5, 2002, Washington, DC

NCD weighed in on the congressional reauthorization of the Individuals with Disabilities Education Act (IDEA) with recommendations on monitoring and enforcement, funding, discipline and over-representation.

NCD's report, *Individuals with Disabilities Education Act Reauthorization: Where Do We Really Stand?*, provides an examination of public testimony, briefing remarks and national research highlighted during the current congressional IDEA reauthorization process. The data and information examined are drawn from public comments received in response to NCD's IDEA working paper; information collected by NCD's Youth Advisory Committee; hearings held by the President's Commission on Excellence in Special Education, committees and subcommittees in the U.S. House of Representatives and U.S. Senate, and the U.S. Commission on Civil Rights; and publications from the National Academy of Science, the Harvard Civil Rights Law Project and the General Accounting Office.

NCD's primary concern about the reauthorization of IDEA is and always will be the nearly six million children and youth with disabilities and their families who should be the beneficiaries of this civil rights law.

IDEA's basic premise is that all children with disabilities have a federally protected civil right to have a free appropriate education that meets their schooling and related service needs in the least restrictive environment. NCD's recommendations on IDEA will go a long way in that regard.

NCD's recommendations are as follows:

1. Enforcement: NCD recommends that the Act include instructions to the Department of Education to more carefully review state regulations and provide instructions and technical assistance in instances where the state rules include unnecessary paperwork requirements or regulations to ensure implementation requirements that adhere to the law without creating unnecessary paperwork.

2. Enforcement: NCD recommends an expansive role for the Department of Justice (DOJ). Congress should authorize and fund DOJ to independently investigate and litigate IDEA cases, as well as administer a federal system for handling pattern and practice complaints filed by individuals. NCD also recommends adequate funding for DOJ and the Department of Education enforcement, complaint-handling and technical assistance infrastructures, enabling the federal agencies to support improvements in state compliance and ensure better outcomes for children.

3. Standards: NCD recommends that the Departments of Education and Justice be directed to develop national compliance standards, improvement measures and enforcement sanctions that will be triggered by specific indicators and measures indicating a state's failure to ensure implementation of the law. Stakeholders, including students with disabilities and parents, should be consulted by the Departments for consistency and clarity as they develop and implement a range of enforcement requirements.

4. Technical Assistance Networks: To fund these Department of Education-sponsored technical assistance programs activities, we recommend that IDEA include a formula that triggers additional funding equal to 10 percent of every IDEA Part B increase. The Department of Education should ensure that this capacity building occurs across the board at state and local school district levels as well, to strengthen all accountability connections.

5. Accountability: NCD recommends that the reauthorization of IDEA mandate reporting for all students with disabilities in the state accountability reports and that the individualized education plan be required to address the need for alternate assessments and individualized accommodations. Schools should be carefully monitored on this issue to ensure that students are not being moved to alternative schools to "protect" the school from lowered scores on the schoolwide tests.

6. Funding: NCD joins the voices of concern from individuals with disabilities, their families and their advocates across the country about inadequate funding for special education. NCD recommends that Congress adopt mandatory funding in keeping with the original commitment from the Federal Government to fund 40 percent of the per pupil cost of special education. In this regard, NCD also recommends that Congress tie full funding of IDEA to full enforcement of IDEA.

7. Discipline: NCD recommends that the current discipline requirements be carefully examined and simplified where possible, without eliminating any protections for students with disabilities. No cessation must remain an absolute requirement in the law.

8. Over-representation of Diverse Populations in Special Education: NCD strongly supports recommendations that the over-representation issue be tackled head on with early intervention and prevention services in the early years and into general education, funded through Title I and other so designated funds. Additionally, faithful adherence to the law for students determined

eligible for services would fix these problems, providing a free appropriate public education in the least restrictive environment, supports and all the other promises of the law.

9. Culturally Appropriate Training Materials: NCD recommends that the law support the Office of Special Education and Rehabilitative Services in the Department of Education to expand its initiatives to serve non-English-speaking groups and/or people with limited English proficiency and create culturally appropriate training materials.

NCD Releases Annual Disability Progress Report
July 26, 2002, Washington, DC

On the 12th anniversary of the Americans with Disabilities Act, NCD released its annual *National Disability Policy: A Progress Report.*

The report covers the period from December 2000 through December 2001, the end of the first session of the 107th Congress. It reviews federal policy activities by issue areas, noting progress where it has occurred and making further recommendations where necessary to the executive and legislative branches of the Federal Government.

Significant barriers, however, still exist for individuals with disabilities who try to participate fully in American society. People with disabilities want to be employed, educated and active citizens in the community. Unfortunately, on average, Americans with disabilities have a lower level of educational attainment and are poorer and more likely to be unemployed than those without disabilities. In today's global economy, America must be able to draw on the talents and creativity of all its citizens.

ADVISORY COMMITTEES

NCD has three advisory committees: Cultural Diversity Advisory Committee, International Watch and the Youth Advisory Committee. All NCD advisory committees are governed by the

Federal Advisory Committee Act (FACA), 5 USC App. 2, which was enacted to promote good government values such as openness, accountability and balance of viewpoints consistent with administrative efficiency and cost-containment.

The following is a summary of the activities of NCD's advisory committees:

Cultural Diversity Advisory Committee

The purpose of NCD's Cultural Diversity Advisory Committee (www.ncd.gov/newsroom/advisory/cultural/cultural.html) is to provide advice and recommendations to NCD on issues affecting people with disabilities from culturally diverse backgrounds. Specifically, the committee will help identify issues, expand outreach, infuse participation and elevate the voices of underserved and unserved segments of this nation's population. This will help NCD develop federal policy that will address the needs and advance the civil and human rights of people from diverse cultures.

Meeting dates:
November 7, 2001
March 6, 2002

International Watch

The purpose of International Watch (www.ncd.gov/newsroom/advisory/international/international.html) is to share information on international disability issues and to advise NCD on the development of policy proposals that will advocate for a foreign policy that is consistent with the values and goals of the Americans with Disabilities Act. International Watch has two working groups: International Convention on the Human Rights of People with Disabilities and Inclusion of People with Disabilities in Foreign Assistance Programs.

Meeting dates:
September 26, 2003
November 21, 2002

Youth Advisory Committee

The purpose of the Youth Advisory Committee (www.ncd.gov/newsroom/advisory/youth/youth.html) is to provide advice to NCD on various issues such as NCD's planning and priorities. NCD is seeking this type of input in order to make sure NCD's activities and policy recommendations respond to the needs of youth with disabilities.

Meeting Dates:
February 27, 2002
April 10, 2002
June 13, 2002

INFORMATION DISSEMINATION

Information dissemination continued to grow at record levels for NCD, as it responded to thousands of telephone calls, e-mail messages and letters from concerned people and organizations about disability issues. In addition, NCD published its monthly newsletter, *NCD Bulletin*, which reaches more than 13,000 people and organizations. All NCD publications are available in alternative formats, such as braille, large print and audiocassette. This information is also available at NCD's award-winning Internet Web site (www.ncd.gov), which now receives more than three million hits per year.

NCD QUARTERLY MEETINGS

As required by Section 400(3)(c) of the Rehabilitation Act of 1973, as amended, NCD met on four occasions during fiscal year 2001. In addition, NCD also met once by conference call.

November 5–6, 2001; Washington, DC

February 4, 2002; Washington, DC

June 10–11, 2002, Washington, DC

August 19–20, 2002, Los Angeles, CA

APPENDIX

Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The overall purpose of NCD is to promote policies, programs, practices and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other

officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness and impact of the Americans with Disabilities Act of 1990 (42 USC 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration and the collection, dissemination and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became the Americans with Disabilities Act. NCD's present list of key issues includes improving personal assistance services, promoting health-care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology and ensuring that those persons with disabilities who are members of diverse cultures fully participate in society.

Statutory History

NCD was initially established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

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